



EAPC **Atlas of Palliative Care** **in Europe 2013** Full Edition

Carlos Centeno
Thomas Lynch
Oana Donea
Javier Rocafort
David Clark



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Universidad
de Navarra
Institute for Culture and Society



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EAPC Atlas of Palliative Care in Europe 2013 - Cartographic Edition

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1. Introduction



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The EAPC Atlas of Palliative Care in Europe 2013 Full Edition, has been developed by the EAPC Task Force on the Development of Palliative Care in Europe in conjunction with the ATLANTES Research Group, Institute for Culture and Society, University of Navarra, Spain.

The University of Glasgow contributed to the project through the active participation of Professor David Clark and with financial support from its Knowledge Exchange Fund for both the printed and electronic versions of the Full and the Cartographic Editions of the Atlas 2013.

National Collaborators

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About EAPC

The European Association for Palliative Care (EAPC) was established on 12 December 1988, with 42 founding members following important initiatives by Professor Vittorio Ventafridda and the Floriani Foundation. The aim of the EAPC is to promote palliative care in Europe and to act as a focus for all of those who work, or have an interest, in the field of palliative care at the scientific, clinical and social levels.

Since 1990 the Head Office of EAPC has been based at the Division of Rehabilitation and Palliative Care within the National Cancer Institute in Milan. In 1998 the EAPC was awarded the status of NGO – Non Governmental Organisation of the Council of Europe, and was transformed to “Onlus” (Non-profit organisation with social utility).

By 2013, the EAPC had individual members from 47 nations across the world, and collective members from 54 National Associations in 32 European Countries, representing a movement of many thousands of health and social care workers and volunteers contributing to palliative care.

More information: <http://www.eapcnet.eu>

MISSION STATEMENT: The EAPC brings together many voices to forge a vision of excellence in palliative care that meets the needs of patients and their families. It strives to develop and promote palliative care in Europe through information, education and research using multi-professional collaboration, while engaging with stakeholders at all levels.

About ICS

The Institute for Culture and Society (ICS) was created to help fulfil one of the principal objectives of the University of Navarra; namely to further the study of Humanities and Social Sciences.

Through international, academic debate, the ICS aspires to establish an authentic dialogue in search of scientific answers, practical ideas, innovative proposals and other relevant contributions to help resolve the principle challenges of today's society.

Within the ICS (and in collaboration with prestigious experts from countries throughout the world), research is promoted with the goal of developing projects of high scientific quality and social relevance in the following four areas: Poverty and Development; Family, Education and Society; Contemporary Art; Globalization, Human Rights and Interculturalism.

About ATLANTES

In 2012 the Institute for Culture and Society (ICS) embarked upon the ATLANTES Research Program "Human dignity, advanced illness and palliative care". The work of the program is interdisciplinary, international and with a strong focus on the contribution of the humanities and social sciences, and with the goal of improving scientific and public understanding of the work of palliative care.

The overall objective of this five-year program is to promote in society a positive attitude toward the care of patients with advanced, irreversible illness, from a perspective based on the dignity of the person and the role of medicine itself. ATLANTES will adopt perspectives from history, psychology, sociology and anthropology to illuminate the understanding of palliative care. It will also encompass contributions from public health, geography, communication studies and education.

ATLANTES will promote reflection on fundamental aspects of palliative care as well as the implementation of strategies to promote palliative care at institutional, professional and societal levels.

Among its sub-projects will be a study of the intangibles in the interaction between palliative care and the individual; the anthropological and spiritual foundation of palliative care; a ranking of the development (and associated Atlases) of palliative care in both Europe and Latin America; education in palliative medicine, a workshop on "The message of palliative care" and a Think Tank on ethics and advanced illness.

ATLANTES will approach these issues in a manner consistent with the work of an academic institution: scientific investigation, professional training and dissemination of the knowledge acquired. This will be done in ways that are consistent with the institutional characteristics of the University of Navarra, and with a clear willingness to co-operate with other institutions that work for similar objectives, as well as those who may adopt differing perspectives.

More information: <http://www.unav.es/centro/cultura-y-sociedad/>

Preface



Professor Sheila Payne
PRESIDENT OF THE EUROPEAN
ASSOCIATION FOR PALLIATIVE CARE

First, I would like to extend my thanks to Carlos Centeno for his leadership and all that he has done to complete the revised EAPC Atlas of Palliative Care in Europe 2013. Clearly this Atlas was not the result of the efforts of one person, and my warm congratulations go to the whole team who have been devoted to revising, reviewing, collecting, collating and interpreting the data that underpin this document. All the authors are members of the EAPC Task Force on the Development of Palliative Care and some of them, are also members of the ATLANTES Research Team of the University of Navarra, Spain. I also wish to acknowledge all those people who have contributed data from their own countries by completing the formidable questionnaire so rigorously. I hope that you will feel that your efforts are rewarded in the revised Atlas.

This work is one of the outcomes of the EAPC Task Force on the Development of Palliative Care in Europe, which was started ten years ago in 2003, by Carlos Centeno, who chaired the group. The EAPC has a number of Task Forces which are time-limited international working groups, often involving leading experts that focus on a specific set of goals. In many senses, they are one of the most important 'engines' of the EAPC and it is both amazing and impressive what groups of like-minded individuals can achieve when they work together. Please see the EAPC website for information on other Task Forces working in the areas of Clinical Care, Education, Organisation and Policy, and Special Groups requiring palliative care. The outputs of these Task Forces are often published as EAPC 'white papers' (position statements), clinical guidelines, curriculum recommendations or consensus papers, and are widely regarded as important for informing policy, practice and education in Europe and beyond.

I am confident that the palliative care country reports from 46/53 participating countries, describing the quantitative and qualitative situation of palliative care development across Europe, will be influential in promoting and guiding further improvements in services. The first EAPC Atlas was widely cited and a 'best seller'! The revised Atlas will provide opportunities for benchmarking across countries, and for comparative analysis of development since 2007. The clear presentation of the tables and maps makes them very easy to use, and shows in a very visually attractive way the work of clinical teams, units, hospices and services, and celebrates the work of thousands of health and social care professionals and volunteers – a real community of effort.

Note from the authors

The European Association for Palliative Care (EAPC) Task Force on the Development of Palliative Care in Europe was established in 2003, with the aim of providing up-to-date, reliable and comprehensive information and analysis about the scope of palliative care across the whole of Europe - defined by the World Health Organisation as a region of 53 countries. Since 2004, the Taskforce has produced a series of papers in scientific and professional journals and in 2007 it published the first EAPC ATLAS OF PALLIATIVE CARE IN EUROPE. The work of the Task Force has also been disseminated through the EAPC website, in presentations and conferences and has been widely used by palliative care professionals, policy makers and healthcare providers.

In this second edition of the ATLAS we have sought to improve our methods of data collection, to refine our techniques of verification and comparison and to further improve the quality of the resulting analysis. Studying the development of palliative care on this scale brings many challenges and we have been grateful for the encouragement, advice and critique of colleagues who, over the years, have taken an interest in our work.

For the present publication, the two key questionnaires ('Facts' and 'Eurobarometer') have been significantly reworked, particularly in the light of the definitions proposed in the EAPC *White Paper on Standards and Norms for Hospice and Palliative Care*. We have included in the questionnaires a typology of services and a glossary of terms to guide those completing the documents, which were distributed to a network of palliative care experts and key persons in the second part of 2012.

Inevitably, in an endeavour of this kind we continue to have to work with 'best estimates' and figures provided to us by in-country palliative care experts. We also give due weight to the opinions of palliative care leaders on current developments and 'hot topics'. For this edition of the ATLAS we have chosen the experts following nominations from individual National Associations (where these exist) and when not possible, we have made use of an extensive network of contacts based on previous studies and bibliographic searches.

In addition, during the early months of 2013, we subjected each draft 'country report' to verification and in-country peer review by external reviewers and in close contact with National Associations. A study of this kind has clear limitations, and these we continue to seek to overcome, but we are confident that, with these methods, we are offering the best available description of the situation of palliative care in Europe in 2012.

Because dissemination and impact are fundamental to a work of this kind, we have devised two different editions of the ATLAS. The EAPC ATLAS OF PALLIATIVE CARE IN EUROPE 2013 - FULL VERSION is available in electronic format only - with more than 400 pages and with extended country reports, a detailed section on methods and including the research instruments and glossary. This will be available from websites in the usual way, but we have also have created versions for electronic platforms accessible by smart phones and tablets.

In contrast, the EAPC ATLAS OF PALLIATIVE CARE IN EUROPE 2013 - CARTOGRAPHIC EDITION is designed for both print format and electronic publication and we have developed this new edition with maps, tables and country reports of one page each, for quick consultation and for use in advocacy activities or reports for policy makers and healthcare providers.

Following on from this new edition of the ATLAS, we will develop our analyses in a series of further scientific papers and reports, concerned with ranking issues, trends in development, thematic aspects and case studies.

In exploring the extensive and varied dimensions of palliative care in the European context - and in working with others who share similar ambitions elsewhere (for example in Latin America) - we continue to have one goal. We seek to provide evidence in support of the wider improvement of palliative and end of life care across populations and jurisdictions, ensuring better access to appropriate care for all who require it - regardless of diagnosis, social group or geography.

We thank all of those who have collaborated in the collection of information or who have assisted in the production of this work. Any errors are those of the EAPC Task Force alone. We welcome comments, suggestions or corrections for further improvement, as the work of the Task Force continues.



The EAPC Task Force on the Development of Palliative Care in Europe: David Clark, Oana Donea, Carlos Centeno, Thomas Lynch and Javier Rocafort.

Aims and objectives

The main aim of this study is to provide an updated, reliable and comprehensive analysis on the development of palliative care within each European country, in order to generate and disseminate an 'evidence base' of clear and accessible research-based information concerning the current provision of the discipline across the WHO European region.

It is hoped that this overview of palliative care provision, achievements and challenges will provide governments and policymakers with a new understanding of the development of programmes to promote palliative care within the WHO European region and that this will, in turn, have a positive impact upon providers of palliative care services in a direct, practical way through an improvement in the development of policy and practice and future service design.

The objectives of the project are:

- To provide a comprehensive analysis of the development of palliative care in the WHO European region in a manner relevant to the EAPC; to inter-governmental organisations and to national and regional governments.
- To explore the current organisation of hospice and palliative care in Europe considering political and social issues; healthcare policies, and the availability of palliative care resources countrywide.
- To facilitate access to information and communication between hospice and palliative care associations and societies that operate across the WHO European region.
- To aid the identification of key persons who have studied the development of hospice and palliative care in their own settings and who may provide country specific data to assist policy makers, planners and professional associations.
- To promote the development of palliative care across the WHO European region.

The main aim of this study is to provide an updated, reliable and comprehensive analysis on the development of palliative care within each European country

Methods

WORKING CONCEPT OF 'PALLIATIVE CARE DEVELOPMENT'

The focus of this publication is on the development of palliative care in Europe.

Development in this context refers to processes, structures, policies and resources that support the delivery of palliative care.

The World Health Organisation (WHO) has defined palliative care and our purpose is to understand how it is being delivered, through designated specialist services but also through integrated approaches that incorporate palliative care into the mainstream of health and social care provision.

This working concept suggests that the number and range of specialized and non-specialized services, in combination with other quantitative and qualitative indicators, can indirectly estimate the development of palliative care at a national level.

The Latin American Association for Palliative Care (ALCP) recently developed a set of indicators to monitor palliative care in countries and regions following the World Health Organization (WHO) public health model. The authors acknowledge other indicators may be developed by each country or organization (for example, the categories constructed for the Worldwide Palliative Care Alliance global mapping of palliative care project).

GROUP OF RESEARCHERS: THE TASK FORCE

The Task Force team members are from different countries and backgrounds and bring wide-ranging experience to the work (Table 1). Most have worked in the Task Force since 2003. For this edition of the Atlas a new member, Oana Donea, joined the team to provide a perspective from Eastern Europe including the sense checking of country reports from Central and Eastern Europe. The experience of Thomas Lynch from several other projects on the development of palliative care in countries of the Commonwealth of Independent States was of value in contacting professionals in those countries.

Table 1. Background and experiences of current members of the EAPC Task Force on the Development of Palliative Care in Europe.

| RESEARCHER | COUNTRY | BACKGROUND | CURRENT PROJECTS |
|------------------------|-------------------------|---|--|
| Carlos Centeno | Spain | Oncology and Palliative Medicine | Palliative Medicine Physician at the Clínica Universidad de Navarra Associate Professor for Palliative Medicine in University of Navarra Researcher at Institute for Culture and Society (ICS), University of Navarra |
| Thomas Lynch | United Kingdom Spain | International hospice and palliative care research | Researcher at International Observatory on End of Life Care, Lancaster University Researcher at Institute for Culture and Society (ICS), University of Navarra Researcher on several other projects on development of Palliative Care in Central and Eastern Europe and the Commonwealth of Independent States |
| Oana Donea | Romania | Oncology and Palliative Care | President of the Association for Mobile Palliative Care Services, Bucharest, Romania Home care service physician and team director |
| Javier Rocafort | Spain | Family Medicine Hospital Management, Palliative Medicine | Palliative Medicine Physician and Medical Director of Laguna Hospice Hospital, Madrid |
| David Clark | United Kingdom | Medical Sociology, History, palliative care development worldwide | Director of the Dumfries Campus of University of Glasgow and Professor at the School of Interdisciplinary Studies, University of Glasgow, Dumfries |

CONCEPTUAL FRAMEWORK AND TYPOLOGY OF PALLIATIVE CARE

The table below shows the conceptual framework that was used in the EAPC Atlas of Palliative Care in Europe. The table is based on different modes of provision of palliative care, classified by place of attendance and level of intervention. In the present study, only data is required that relates to specialist palliative care services (not the basic level of care provided by palliative care professionals working in traditional health care settings).

The definitions used in this conceptual framework are adapted from the EAPC White Paper on *Standards and Norms for Hospice and Palliative Care in Europe*. The exception to this is the definition for Mixed palliative care support teams; there is no definition of this term in the EAPC White Paper, therefore the definition used is one compiled by the Task Force. A glossary of terms used was included in the questionnaires and is annexed at the end of this publication.

Table 2. Conceptual framework used in the EAPC Atlas of Palliative Care.

| LOCATION WHERE PALLIATIVE CARE IS PROVIDED | RESOURCES AND SERVICES PROVIDING BASIC LEVEL OF PALLIATIVE CARE | SPECIALIZED PALLIATIVE CARE SERVICES | | | |
|--|---|--|---|---------------------------------------|---|
| | Basic level of palliative care | Specialized palliative care services or supportive palliative care services | | | Other specialized palliative care services |
| Patient care in acute hospitals | General Hospital | Volunteer hospice team | Hospital palliative care support team | Mixed palliative care support team | Palliative care units in tertiary hospitals (acute, university or general hospitals) |
| Patient care (medium and long term) in places other than general hospitals | Nursing homes and other residential facilities | | | | Palliative care units in hospitals or residential non-general hospitals |
| Patient care is provided at home | Assistance is provided by general or family physician and nurses in primary care teams | | Home care support team (the family physician has primary responsibility for the patient) | | Palliative care unit in an inpatient hospice Day hospice or day-care center for palliative care Home palliative care team (primary responsibility for patient within the palliative care team) |

COUNTRY 'EXPERTS' AND NATIONAL LEADERS IN PALLIATIVE CARE DEVELOPMENT

In 2011, the Task Force embarked upon a new programme of work to refine its original methods and to produce updated information on the status of palliative care in each European country. A letter was sent to the President of each National Palliative Care Association announcing the 2012 quantitative 'Facts Questionnaire' and qualitative 'Eurobarometer Survey' and asking them to nominate a 'key person' with extensive local knowledge of palliative care to complete the documents. The Task Force acknowledges the fact that there may be some methodological limitations with the use of 'experts' as a source of palliative care data collection (for example, inaccuracy or bias in responses); it was therefore decided to adopt a multiple informant methodology involving several representatives from different types of palliative care setting and multi-disciplinarity to complete the Facts Questionnaire and Eurobarometer Survey. Strict guidelines were followed and the relevant information is provided in this publication – how they were identified and recruited; design of the questionnaire and validation of the data provided (peer review).

If a country either had no National Palliative Care Association or the President of an association failed to respond to this request, 'key persons' were selected either through previous participation in the original Task Force project, personal recommendation from existing 'key persons' or other palliative care sources, or on the basis of being known to members of the Task Force whilst participating in other similar palliative care-related projects. The EAPC Head Office, the *International Association of Hospice and Palliative Care* (IAHPC), *Help the Hospices* (HTH) and the *International Observatory on End of Life Care* (IOELC) provided vital information in identifying national associations, local contacts, and key palliative care workers in each country and region.

In total, 89 'key persons' from 49 countries of the WHO European region were identified to complete the Facts Questionnaire and Eurobarometer Survey; in nine countries (18%), the same person was requested to complete both documents as they were either the only person that could be identified as being actively involved in palliative care or they were specifically chosen as the most suitable to complete both the Facts Questionnaire and Eurobarometer Survey by their National Palliative Care Association: 33 (37%) were either members of their National Palliative Care Association or recommended by them; 33 (37%) had previously participated in the original Task Force project; 11 (12%) were recommended by their National Palliative Care Association and had previously participated in the original Task Force project; and 11 (12%) were personal recommendations from existing 'key persons' or other palliative care sources, or selected on the basis of being known to members of the Task Force whilst participating in other similar palliative care-related projects.

In four countries of the 53 in the WHO European region, it was not possible to identify even one 'key person' working in palliative care due to either the small size of the country (Monaco and San Marino) or because it was a Commonwealth of Independent States country where establishing lines of communication proved to be especially difficult (Turkmenistan, Uzbekistan).

QUANTITATIVE STUDY: FACTS QUESTIONNAIRE

The Facts Questionnaire collected 'factual' data on palliative care service provision in each European country; this quantitative survey is known as the 'Facts Questionnaire'. The initial Facts Questionnaire gathered data on the availability, organisation and delivery of palliative care: for example, the number and type of specific resources available; the number and type of professionals involved; the target population; the funding of services; and the accreditation of professionals. Combining data obtained through the Facts Questionnaire with other data on the state of palliative care enabled the production of an overall ranking system that facilitated a comparison of the development of the discipline between countries and regions.

The Facts Questionnaire was revised by the Task Force at a meeting of all members at Laguna Hospital in Madrid in 2011. The new format differs significantly from the original version; for example, the sections on 'Palliative Care Workforce Capacity', 'Palliative care Population' and 'Palliative Care Funding' in the original version have been completely removed as no data from those sections had been utilised within the compilation of publications. The 2011 version contains a 'conceptual framework' to be used as a point of reference for 'key persons' completing the questionnaire; this framework is based on different modes of provision of palliative care, and classified by place of attendance and level of intervention. In particular, there was an acknowledgement within the 2011 Facts Questionnaire that definitions of palliative care services may differ between countries and regions. In this context, a new section on specialized palliative care services was developed based on the EAPC White Paper on Standards and norms for Hospice and Palliative Care in Europe. Part 2 (European Journal of Palliative Care, 2010; 17(1): 22-33). There are also new sections on education and training, policy development, and the 'vitality' of palliative care in each country. Some questions relate to the work of other EAPC Task Forces (for example, EAPC Task Force on Education) and external authors were consulted to compile questions on specific palliative care issues (for example, geriatric palliative care). The lengthy process of amendment that the Facts Questionnaire had been subjected to constituted a form of 'internal piloting' and resulted in considerable improvement on the 2006 version.

In October 2011, a formal letter accompanied by the Facts Questionnaire was sent to the identified 'key persons', describing the work of the Task Force and inviting them to take part in the project. In addition to the four countries where no 'key person' could be identified, there were a further three countries where it had been possible to identify a potential 'key person' but they failed to respond to requests to complete the Facts Questionnaire (Bosnia-Herzegovina, Kyrgyzstan, Tajikistan). A total of 46/53 countries from the WHO European region therefore completed the 2012 EAPC Facts Questionnaire (87%). This compares to 44/52 European countries that completed the questionnaire in the previous project (85%).

QUALITATIVE STUDY: EUROBAROMETER SURVEY

Qualitative information on the background situation of palliative care in each country has been generated by the Eurobarometer Survey. It is used to illuminate the socio-cultural context within which the quantitative data from the Facts Questionnaire is positioned. In the Eurobarometer Survey, the provision of palliative care is considered within the wider milieu of health care policy, as well as social, ethical and cultural factors. Central to the ability to improve access to palliative care in Europe is the ability to understand the barriers that prevent those who need palliative care from receiving it at all levels within healthcare and legislative systems; barriers to the development of palliative care in each country are critically examined from data gained within the Eurobarometer.

The initial Eurobarometer Survey had five main sections:

- Background questions (name, contact details, palliative care organisation, etc.);
- Questions on the current state of development of palliative care in each country (has improved; remained the same; got worse, etc.);
- Questions on barriers to, and opportunities for, the development of palliative care in each country (for example, availability of opioids; other issues relevant to the development of palliative care);
- Questions on policy (for example, national health policies; euthanasia and assisted suicide; Recommendations on Palliative Care from the Council of Europe (2003);
- Questions on the future of palliative care in each country.

The Task Force revised the Eurobarometer Survey in 2011 at a meeting of all members at Laguna Hospital in Madrid. There are new sections on essential medication for pain and symptom management, palliative care education and training initiatives, and the socio-cultural, ethical and moral issues surrounding palliative care. As palliative care is coming to be regarded as a human right, and access to palliative medication has been incorporated into a resolution of the United Nations Commission on Human Rights, the Eurobarometer also contains new questions to reflect growing interest in these issues.

In October 2011, a formal letter accompanied by the Eurobarometer Survey was sent to the identified 'key persons', describing the work of the Task Force and inviting them to take part in the project. In addition to the four countries where no 'key person' could be identified (Monaco, San Marino, Turkmenistan, Uzbekistan), there was another country where it had been possible to identify a potential 'key person' but they failed to respond to requests to complete the Eurobarometer Survey (Tajikistan). A total of 48/53 countries from the WHO European region therefore completed the 2012 EAPC Eurobarometer Survey (91%). This compares to 44/52 European countries that completed the survey in the previous project (85%). Unfortunately, although 48 countries completed the Eurobarometer Survey, Bosnia-Herzegovina and Kyrgyzstan failed to complete the Facts Questionnaire and a country report could not therefore be fully completed.

PEER REVIEW PROCESS AND SENSE CHECKING

The Task Force determined that 'sense-checking' would be undertaken to confirm the accuracy of the Facts Questionnaire data. This was achieved by cross-checking with data from other projects that Task Force members have been involved with and utilising the vast palliative care experience and knowledge within the Task Force itself. However, it was also agreed that the completed EAPC Country Report (incorporating both the completed Facts Questionnaire and Eurobarometer Survey) should be sent to either the President of the National Association in a particular country (where a National Association exists), or to a second/third 'key person' for peer-review. This enhanced the reliability and credibility of both documents.

In Summer 2011, a letter was sent to the President of each National Palliative Care Association requesting a list of potential contacts that could be used to peer-review the completed documents. As with the Facts Questionnaire and Eurobarometer Survey, a multiple informant methodology was utilised involving several representatives from different types of palliative care setting and multi-disciplinarity. National Palliative Care Associations in 22/25 (88%) countries each provided details of three individuals that they felt were suitable to undertake the peer-review process of the completed country reports. Other sources for identifying individuals to complete the peer-review process were through previous participation in the original Task Force project, personal recommendation from existing 'key persons' or other palliative care sources, or on the basis of being known to members of the Task Force whilst participating in other similar palliative care-related projects. The EAPC Head Office in particular provided much assistance in identifying such individuals.

In total, 43/46 (93%) of the completed country reports were peer-reviewed by one to three autonomous 'key persons' from that particular country; three country reports could not be subjected to the peer-review process as there was only one person able to be identified as a 'key person' (the original respondent). Although there were a total of ten countries where only one 'key person' could be identified when the original Facts Questionnaire and Eurobarometer Survey were distributed, by the time of the peer-review process there was only Andorra, Estonia, and Montenegro where this was the case.

The Task Force determined that 'sense-checking' would be undertaken to confirm the accuracy of the Facts Questionnaire data

BIBLIOGRAPHIC SELECTION

In 2006, the first edition of the Atlas of Palliative Care in Europe undertook a systematic review of articles on national development published in the ten-year period up to 2005; two main databases were used for this purpose - PUBMED and CINAHL. The review found more than 300 articles which were selected following a peer-review process and filtering by title and abstract. The review made it possible to witness the progress and changes in palliative care in each country. It also provided a detailed summary of the references, and permitted identification of key people who reported on the development of palliative care in those countries.

In the current edition of the Atlas, the literature search and selection criteria were updated and broadened. A combined total of 3,430 new articles were considered for the period 2006 - 2012 in both databases, (PUBMED and CINAHL). The search criteria were: "Palliative medicine" (MeSH) OR "Palliative care" (MeSH) OR "Terminal care" (MeSH) AND "Country" (MeSH). Initially, eleven countries were found that had no results matching the specified criteria, 18 countries which results showed less than ten relevant articles, and 24 countries in which ten or more relevant articles were found. All these articles passed through a double filter (title and abstract selection by an expert in documentation management and a researcher of the Task Force). After this process of double filtering, 142 articles relating to the development of palliative care on a national level between 2006 and 2012 were discovered: 21 countries did not have any relevant articles; 23 countries had less than ten; and nine countries had ten or more relevant articles. In countries where there were less than ten relevant articles, articles from the previous project were selected. Eventually, a total of 213 bibliographic references were selected for inclusion in this edition of the Atlas.

ADDITIONAL METHODS

In addition to the three original Task Force methods (Bibliography, Facts Questionnaire and Eurobarometer Survey), a further approach was added: an EAPC Survey from Head Office that provides information on:

- National Associations;
- Numbers of people attending EAPC Congresses;
- Numbers of people checking the EAPC website;
- Initiatives relating to World Hospice and Palliative Care Day;
- Numbers of people in the EAPC Database.

It was agreed that the additional methods should form part of a more comprehensive system of quality assurance and that the Task Force should seek to contextualise data contained within the Facts Questionnaire, by reference to other sources.

CARTOGRAPHY

The cartography has been developed by the Geography Department of the University of Navarra, under the management of Professor Juan José Pons, who has been actively engaged in all Task Force meetings.

For the cartographic version of the Atlas, the digital covers 'World Countries' and 'World Cities' (DeLorme Publishing Company, Inc.) were obtained from the ArcGIS Website (under a Creative Commons license). In both cases, information was updated in October 2011 and the geographic coordinates system used was WGS 1984. The software used for map construction is the ArcGIS program (ESRI) version 10.0.



Part of the ATLANTES research team in a meeting about the Atlas in Pamplona.

The choice of the Cartographic projection (in this case, pseudocylindric Times) is based on the criteria of making the most of the available space, so as to fully represent all countries correctly. Despite this, it has been impossible to avoid removing some of the biggest territories (Russia, Kazakhstan, Finland, etc) and, on some occasions there has been a need to introduce small cartographic licenses, such as amplified squares representing a value for the smallest countries (Andorra, Malta, Luxembourg). The representation scale is 1:25,000,000.

The types of maps utilized for the thematic representation are: choropleths map (basically for "relative data"), symbols map (for absolute data or to highlight determined values presence/absence) and bars and sectorial cartodiagrams.

In terms of representation style, a constant colours "range" has been adopted and used throughout this publication: blue for choropleths and "reds" for symbols and cartodiagrams; this was done to enhance the homogeneity and coherence of the cartographic version as a whole.

In terms of the socioeconomic and health information used in the country reports, the data has been collected mainly from "World Population Prospects: The 2010 Revision of United Nations for the year 2012", and "World Bank" databases, with the clear criteria of finding the most accurate, updated and reliable data for the maximum number of countries of the WHO European region.

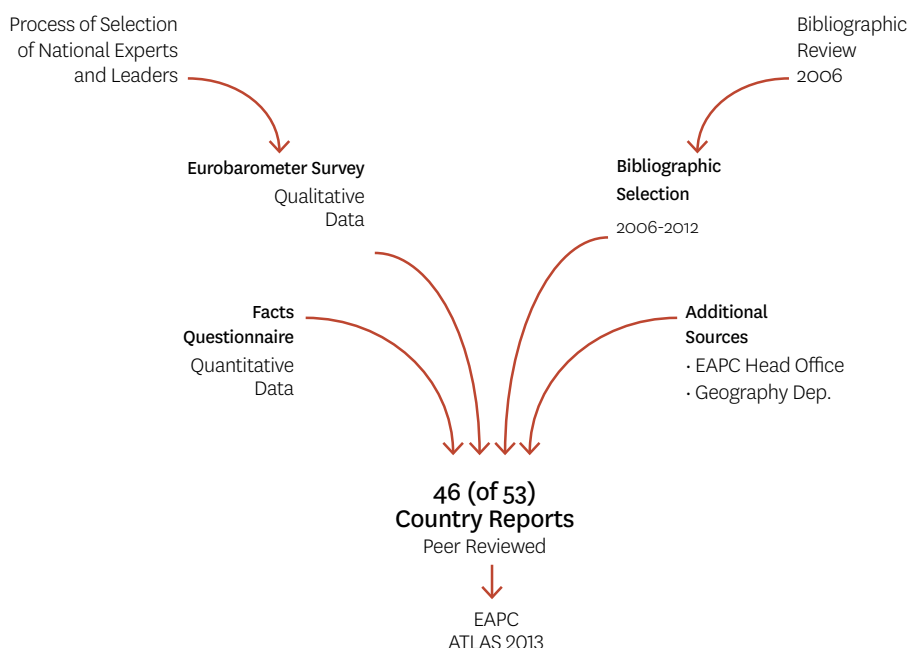
LIMITATIONS AND CONSTRAINTS

This work has built on lessons learned from the earlier Task Force studies. It addresses limitations and constraints associated with standardisation of terminology relating to hospice and palliative care services. It also addresses some of the unintended negative effects that may occur when benchmarking studies are undertaken. There may have been a failure to acknowledge the role of 'human agency' within the process of collecting the data – the fact that occasionally there could be the potential for data provided by a small number of 'key persons' to become 'slightly exaggerated', that there could be disagreement on data provided by two National Palliative Care Associations in the same country, or that there may be 'competitive tendencies' between neighbouring countries and regions.

The Task Force always aims to work with best estimations or exact figures from experts in the field of palliative care; leading opinions on important palliative care topics were also collected from 'key persons' in each respective country.

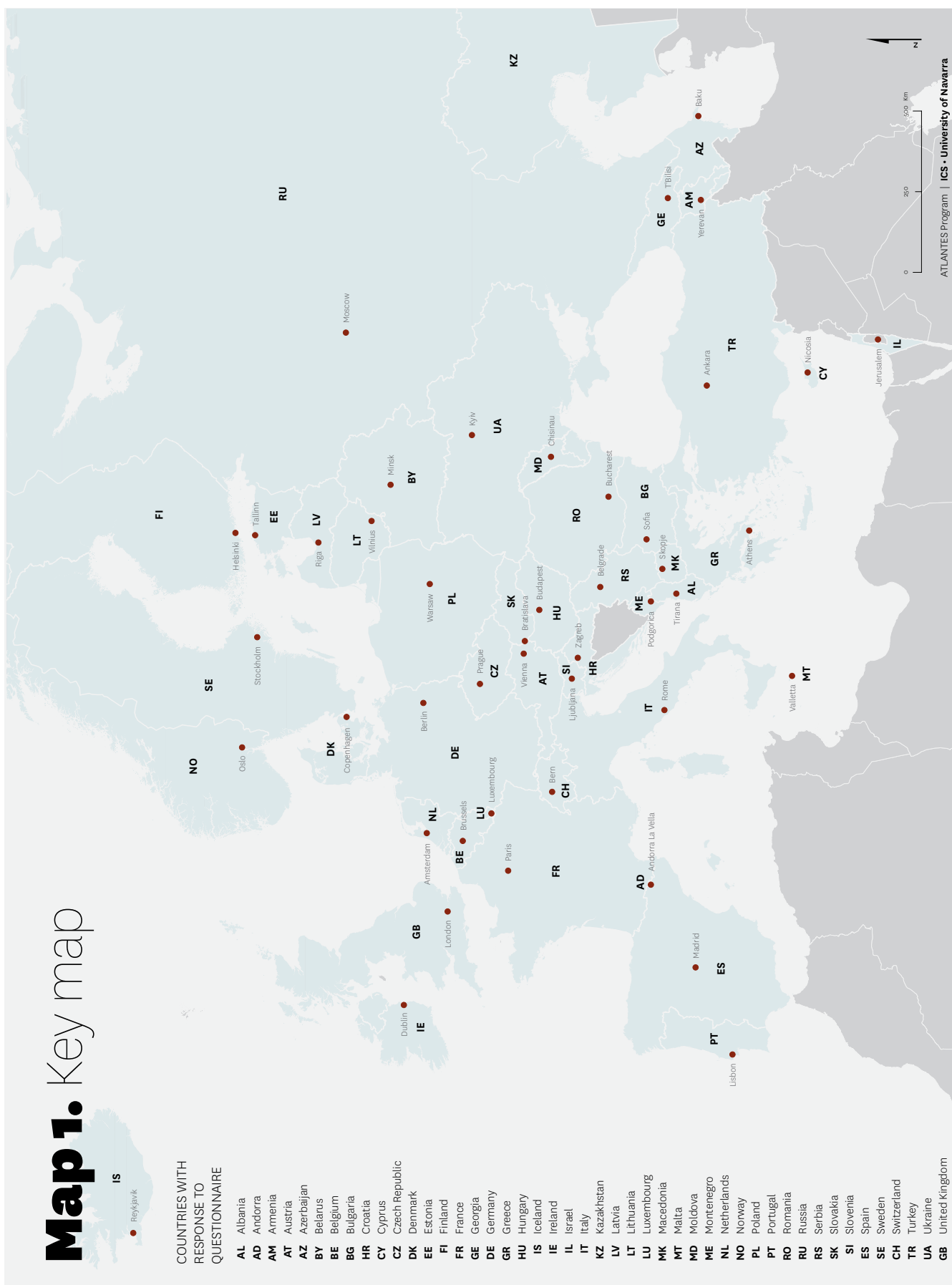
We acknowledge, however, that although opinion leaders and palliative care 'experts' may have attempted to obtain the best information within each country, some of them could have failed in this aim. To overcome this methodological limitation, as detailed at length in the Method Section, for the current project we approached the experts after they were nominated by their National Palliative Care Association; if this was not possible, we used our extensive list of contacts from previous similar studies or information from the bibliographic search. Also (in contrast to our previous project), after completion of the first version of the country report we adopted a broad peer review process throughout the first part of 2013, with at least one external reviewer working in close contact with each National Palliative Care Association. In sum, although a study of this kind has clear limitations, we are convinced that, with the increased rigour that we have used, we are offering the best possible comparative information about the situation of palliative care in the WHO European region.

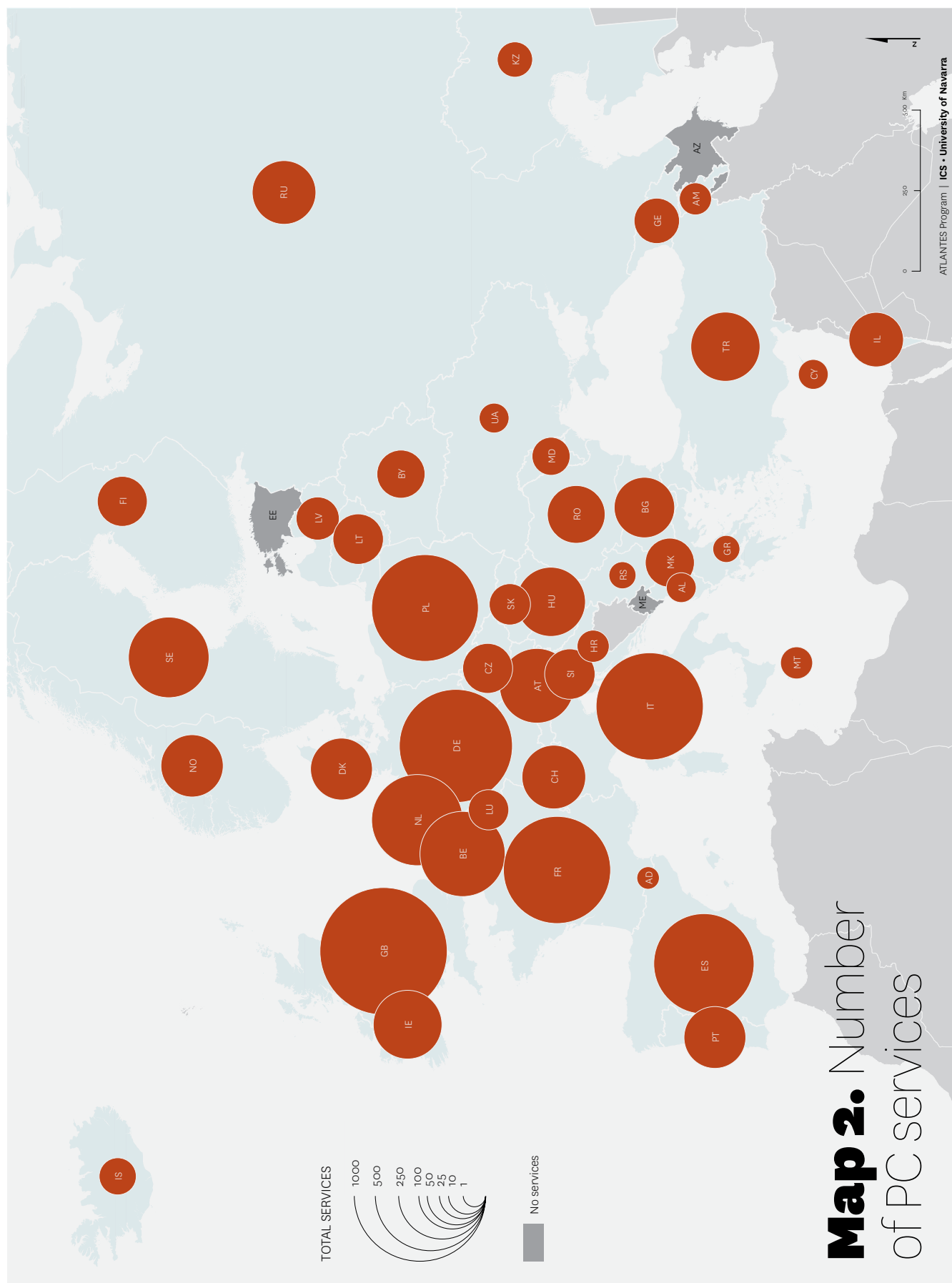
Figure 1. Methods and process of the Atlas survey.

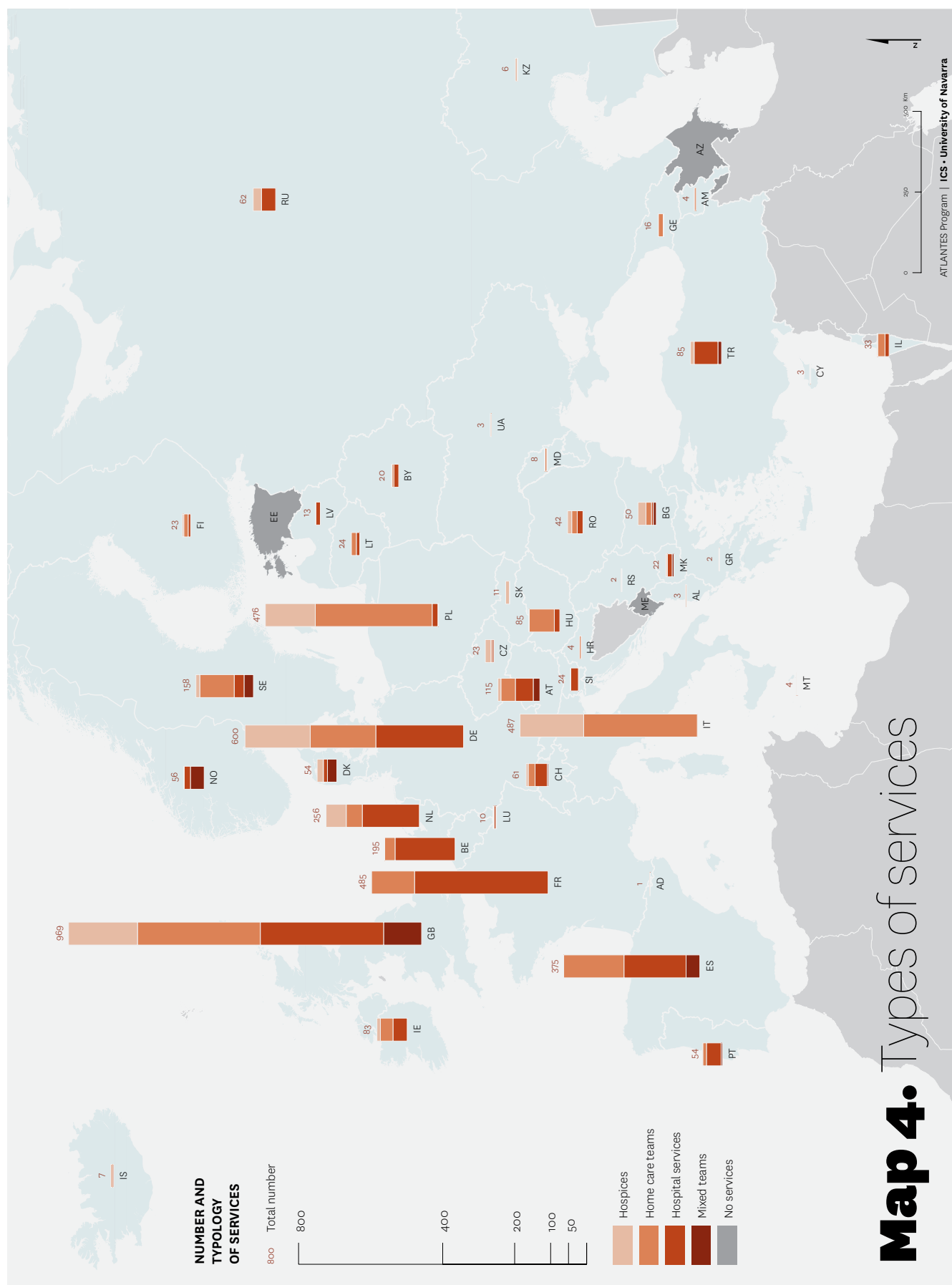




2. Country Reports







Albania¹

NATIONAL ASSOCIATIONS

Family Healthcare Association

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Qendra e Kujdesit Paliativ Korçe*

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | ○ |
| Hospital palliative care support team | ○ |
| Home palliative care support team | 2-6 |
| Mixed palliative care support team | 1-5 (0-8) |
| Palliative care units in tertiary hospitals | ○ |
| Palliative care units in non-tertiary hospitals | ○ |
| Inpatient hospice | ○ |
| Day hospice/day care centre | ○ |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Irena Laska - Korce Palliative Care Center data
- Kristo Huta - Albania Association of Palliative Care (AAPC)
- Albania Needs Assessment Study Research – AAPC

Additional comments:

- There is a general lack of palliative care services in Albanian public hospitals, although the National Palliative Care Working Group is working in collaboration with the Ministry of Health (MOH) to develop such units in some regional hospitals. Palliative care services are available in only five cities in Albania; in four of these cities home care is the only service offered (provided mainly from non-profit organizations). One of the non-profit organizations (Mary Potter) provides respite care service in their unit (in addition to home care). The only inpatient hospice was in operation for five years but was closed due to lack of funds. There is no day care service in Albania.
- There are a few volunteers in the “Mary Potter” Palliative Care Centre but they are not a team qualified to offer palliative care support; they engage mainly in fund-raising activities. The “Mary Potter” Palliative Care Centre team offers home care and mixed palliative care for adults and home care and day therapy for children. There are eight beds in the palliative care centre but patients only receive day care services (it is not an inpatient unit). The Centre also provides training for healthcare professionals (doctors and nurses). Other services offered by the team include chemotherapy application and palliative care education.

Palliative care services for children:

- There is one home care paediatric team; there are two mixed paediatric care support teams and eight mixed paediatric beds available for day care services only.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

- 2002** All governmental and non-governmental associations meet together to form the "Albanian Palliative Care Association" (an umbrella organization for the development of palliative care issues in Albania).
- 2003** The Ryder Albania inpatient hospice for terminally-ill cancer patients is opened.
- 2004** The first home palliative care service for cancer patients commences.

EAPC Palliative Care Eurobarometer Survey, 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- Inclusion of more essential medications in the reimbursed opioid list (for cancer patients only); the prescription of morphine without limit to cancer patients; the completion of National Standards of Palliative Care; finalization of the National Strategic Plan for Palliative Care; issue of a palliative care training manual to be used on a national basis.
- The Second National Palliative Care conference held in December 2010.
- The National Palliative Care Working Group established in 2011 to develop palliative care strategy as part of the national cancer strategy.

Overall progress in hospice and palliative care:

- Has improved (but the improvement is slow and there needs to be more coordination at the local, national, regional and international level).

Development of hospice and palliative care in different health and social care settings:

- Hospitals: no development, but palliative care activists in Albania are working on this issue (a short-term objective that is yet to be accomplished).
- Nursing homes: not available in Albania
- Residential homes for the elderly: not available in Albania
- Other community settings: There are a number of home palliative care teams in Albania; for example, Mary Potter Palliative Care - Korça, Sue Ryder Care - Tirana and Durrës, and Lezhe district, Northern Albania (more than 200 patients have received home care in Lezhe since 2007).

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

There has been no expansion from a focus on cancer patients to address the needs of 'non-cancer' patients.

Perceived barriers to the development of hospice and palliative care:

- (i) The legal limitation that stipulates opioids are only available to cancer patients
- (ii) The lack of palliative care inclusion in the curricula of medical, nursing and social science faculties in the Universities
- (iii) Lack of funds to extend palliative care services throughout the entire country
- (iv) Low level of GDP within the Albanian health care system
- (v) Frequent changes amongst key staff at the MOH which affects the sustainability and effectiveness of lobbying and advocacy initiatives.

Perceived opportunities for the development of hospice and palliative care:

- (i) More than a decade of experience of palliative care provision within the existing teams and their commitment to develop palliative care services
- (ii) AAPC and the National Palliative Care Working Group
- (iii) Continuous palliative care training with healthcare providers across the entire country supported by different donors.

Other issues relevant to the development of hospice and palliative care:

Different seminars, conferences and workshops have been organized since 2006. Several meetings with policy makers have taken place as part of the lobbying and advocacy initiatives undertaken by national palliative care activists. These activities have the support of international experts and donors who are working to develop palliative care in the country.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

The Albanian Palliative Care Association (Shoqata e Kurave Paliative Shqiptare) was formed in 2002 and is representative of the whole country.

Directory or catalogue of palliative care services:

There is no directory or catalogue of palliative care services but there are some published documents from AAPC with data on palliative care services.

Congresses, scientific meetings or scientific journals in palliative care:

- There are two palliative care workshops each year and one conference every three or four years; approximately 50-60 people attend each workshop and 90-100 people attend each conference.
- There are no scientific journals of palliative care.

Palliative care research capacity:

There have been some attempts to increase palliative care research capacity by a small number of physicians, social workers, psychologists and nurses involved in various research projects: for example, a palliative care needs assessment, perception of health professionals and the general public in relation to issues of death and dying, measurement of the effectiveness of training courses on opioid usage, etc.

Palliative care collaboration:

- There are twinning initiatives involving Sue Ryder Care Albania and Korce Palliative Care Center; both these organizations are collaborating with other organizations for the further development of palliative care in Albania.
- There is collaboration with pioneer groups such as Little Company of Mary (London, UK) and also Sue Ryder Care (UK). Little Company of Mary is a congregation of Catholic Sisters that founded palliative care in the Korce Region in 1993. In the same year, Sue Ryder founded palliative care in Tirana. Today, these services continue to be developed by Korce Palliative Care and Sue Ryder Care Albania.
- Many activities and initiatives were held during the week before international World Hospice and Palliative Care Day; for example, fundraising walks for hospices, TV promotion of palliative care, preparation and delivery of leaflets and brochures with information about hospice and palliative care, etc.
- The Palliative Care and Education Centre (PCEC) has partnered with PRIME UK (Partnerships in International Medical Education) in organizing palliative care courses in Northern Albania.
- PCEC is also partnering with SMILE International, and a humanitarian UK NGO working in Kosovo since 1999 that offers palliative care education and home-based palliative care for patients in the Gjakove area.

Worldwide palliative care alliance level of development:

3A (Isolated palliative care provision).

There is now more than a decade of experience of palliative care provision within existing home and mixed palliative care support teams and a commitment to further develop services in collaboration with the Albanian Palliative Care Association

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- All key stakeholders in palliative care have engaged in providing training and education initiatives for doctors and nurses lasting three to nine days duration. Since 2009, residential courses have been organized for health professionals from across the entire country.
- AAPC have drafted and published a standardised palliative care training manual to be used by all the relevant trainers.
- PCEC has organized palliative care courses for healthcare professionals in Northern Albania. More than 13 three-day courses have been organized and more than 500 healthcare professionals have attended these courses.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Ten topics related to palliative care have been integrated into the (mandatory) oncology module in the Faculty of Medicine.
- Nursing: Palliative care is included in mandatory modules in six Faculties of Nursing.
- Social work: Palliative care is included within the (mandatory) health module at the Faculty of Social Sciences.
- Other professions: There is no information available at this time.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: A one-year specialization in palliative care in the Faculty of Medicine is in the process of being approved by the Ministry of Education.
- Nursing: There is no information available at this time.
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Translation of palliative care documents or other materials:

A number of palliative care documents or other materials have been translated: Recommendation REC (2003) 24 of the Committee of Ministers to Member States on the Organization of Palliative Care. Council of Europe; Oncology, Second Edition; What do you need to know about cancer; Morphine and the relief of cancer pain, information for patients, families and friends; Communication skills in palliative care. Neurologic clinics; Symptom control in palliative care; How to talk to someone with cancer; Home care; Chemotherapy – A guide for patients and their family members; Hospice and Palliative Care (the essential guide) – Stephen R. Connor; Hospice Companion (best practices for interdisciplinary assessment and care of common problems during the last phase of life) – Perry G. Fine.

Initiatives to develop healthcare professional leadership in palliative care:

One physician from Ryder Albania Association has attended the Leadership Development Initiative at San Diego Hospice, USA.

Officially recognized medical certification:

There is no official certification in Albania but there is “accreditation in process” as AAPC work on the institutionalization of palliative care in the curricula of Medical and Nursing Universities (to be achieved in 2013); accredited training courses are also available for healthcare professionals (doctors and nurses) at the “Mary Potter” Palliative Care Centre.

Capacity of palliative care workforce training in Universities and Medical Schools:

- There is only one public medical school in Albania situated in Tirana: there is another non-public medical school in Albania (no available information).
- There are a few lecturers at the one State Faculty of Medicine, the six Faculties of Nursing and the Faculty of Social Science who deliver some lectures on palliative care. AAPC is the main organisation engaged in the development of palliative care training and education in the country.
- There are only five specialists that teach palliative care in medical schools. No-one has an academic title in this specialty and there are no full-time teachers of this subject. Under the category of “other professor non-medical”, there are an estimated ten palliative care specialists that train healthcare professionals in this specialty; these specialists are doctors, nurses and social workers.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- Essential medications such as morphine are only available to cancer patients (prescribing regulations exclude other patient populations) but these can be prescribed without limit and there is no maximum length of time that a patient can receive opioids for. There are no different legal requirements for prescribing, dispensing or purchasing dosage forms of the same opioid (i.e. oral, transdermal, injectable). No special training is required for opioid prescribing (but some NGOs offer training in this area).
- However, morphine is only available in 10 mg injection and in 10 mg long-acting tablet form (no immediate-release morphine is available); fentanyl is available but is too expensive to afford: methadone is only available for injecting drug users as part of the HIV program; pethidine is very rarely used: general practitioners can prescribe no more than 100 mg opioids/per day; some opioids are unavailable (there are shortages); to prescribe opioids, a license is required from the Ministry of Health and a contract must be signed with the Insurance Institute of Health Care; special prescription forms are required (approved by the Insurance Institute of Health Care).

Developments/opportunities/barriers relating to the accessibility of essential medications:

- Essential medications are only accessible to cancer patients living in the regions where palliative care is provided.
- There is a centralized regulatory system for the reimbursement of opioids (patients face much bureaucracy).
- Prescriptions are limited to seven days (the validity of a prescription for morphine is only three days).
- Family doctors have a limit on the amount of money available each month for prescribing opioids – if they exceed this amount, severe sanctions are imposed.
- There are a limited number of pharmacies that stock morphine.
- Prescribing is limited to doctors of NGOs, authorized doctors in districts where there is no palliative care service and GP's with a recommendation from an oncologist (in most of the regions there is only one such specialist); nurses are not authorized to prescribe.
- The Government's method for estimating opioid requirements does not take into consideration actual need.

Developments/opportunities/barriers relating to the affordability of essential medications:

- There are no barriers to the affordability of morphine because it is free for cancer patients.
- However, opioids that are not reimbursed are very expensive, and most Albanian patients cannot access them due to lack of affordability.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

Based on the National Cancer Control Program and the National Strategic Plan for Palliative Care, the National Palliative Care Working Group will:

- Propose to the MOH to amend the law from seven to 28 days for treatment duration;
- Propose to the MOH to change the regulation to allow opioid prescription for non-cancer patients with moderate to severe pain;
- Propose to the Health Insurance Institute to remove the daily dose limit of morphine that may be prescribed;
- Propose to the MOH to increase the number of physicians allowed to acquire a license to prescribe (after appropriate education and training in effective and safe prescribing);
- Develop a survey for pharmacists to evaluate their knowledge and attitudes in relation to stocking opioids (results will be shared with the MOH);
- Propose to the MOH an increase in the number of licensed pharmacies and that those pharmacies should be obligated to dispense opioids (one in each town);
- Propose to the Health Insurance Fund that the cost of morphine as an Essential WHO medication is fully covered (make reference to pain relief as a human rights issue – provide 2008 Letter to CND from Special UN Rapporteur).

Initiatives to promote attitudinal change in relation to 'opiophobia':

- There are some publications to promote the importance of morphine as an essential medication for pain relief.
- Six 'opiophobia' seminars have been developed with physicians working in primary care services.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There have been no such initiatives focusing on this special category of persons.

Initiatives that consider access to essential medication as a legal and human right:

The work of all palliative care providers in Albania is guided by this principle.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- The most important change is the inclusion of palliative care in the National Plan of Cancer Control.
- Another important policy change is the approval of the National Standards for Palliative Care by the MOH (2010).
- National Strategic Plan for Palliative Care (2011).
- Action Plan of Palliative Care (2010).
- Legal and economic analysis of palliative care (2011).
- A palliative care law (2012) – drafted and in the process of approval.
- Pilot scheme by the MOH to create a small palliative care team in a regional hospital (October 2012).

The impact of these policy changes and ways in which they have been important:

These changes represent a step forward to the institutionalization of palliative care which will enable further development of services across the entire country.

Development of a national palliative care consensus:

Approval of the National Standards for Palliative Care by the Ministry of Health; finalization of the National Strategic Plan for Palliative Care; issue of a palliative care training manual to be used on a national basis.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

Several meetings are held with stakeholders and policy makers to develop palliative care strategies (at least twice a year).

Development of an advocacy framework for integrating palliative care into the health care system:

Palliative care is not yet integrated into the health care system but AAPC is working hard to achieve such integration (supported and facilitated by international expert Stephen Connor).

Strategies to improve political awareness and government recognition of palliative care:

- Representatives of all key institutions have participated in a number of meetings, conferences and workshops about palliative care. There has also been much media promotion of palliative care services, particularly relating to activities organized to celebrate International World Hospice and Palliative Care Day.
- Actively involving government representatives in all palliative care initiatives.
- Producing facts, statistics and data on the importance of palliative care services.
- Informing government representatives about all palliative care developments within and outside the country.
- Promoting media debate and discussion about palliative care issues.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

There have been funding initiatives from international donors and other palliative care organizations. A small amount of support has been provided by local government (two regions only).

Involvement with the European Union in relation to hospice and palliative care initiatives:

There is no information available at this time.

Development of initiatives framing palliative care as a 'human right':

There have been some activities organized to raise the awareness of palliative care and to demonstrate the necessity of this service for terminally-ill patients as a human right.

General legislation relating to palliative care:

There is legislation in process and AAPC is working with policy makers and governmental bodies to create a law specifically relating to palliative care.

Published national documents relating to palliative care standards and norms:

There are National Standards of Palliative Care, published in January 2011 as a single edition.

National Plan or Strategy of Palliative Care:

The National Strategic Plan for Palliative Care (2011 - 2015) was approved in 2011.

National Cancer Control Strategy:

There is a National Cancer Control Strategy that includes palliative care.

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy but it is not known if it contains an explicit reference to palliative care provision.

National Primary Health Care Strategy:

The National Primary Healthcare Strategy does not contain an explicit reference to palliative care provision.

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

There is no information available at this time.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

There are some translated materials on symptom control, pain management, use of opiates, etc.

Funding of palliative care services:

The majority of funding for the development of palliative care services comes from international donors (Soros foundation; Sue Ryder Care, UK; Little Company of Mary; Spanish and German Caritas; Dorcas Aid; Vodafone Foundation; Czech Embassy; Intesa San Paolo Bank).

More essential medications have been included in the reimbursed opioid list and morphine is prescribed without limit to cancer patients. Palliative care training has been provided throughout Albania and a manual distributed to be used on a national basis

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

There have been some initiatives aiming to change the public perception of hospice and palliative care through raising awareness (media, mobile phone messages, workshops, posters, flyers, etc.).

Major public discussion, debate or controversy about hospice and palliative care:

There are plans for increased public discussion about hospice and palliative care during 2013.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

Representatives of AAPC and other non-profit organizations are engaged in such initiatives with policy and decision makers, and academic staff of the Faculties of Medicine, Nursing, and Social Sciences.

Hospice or palliative care 'success' stories:

Palliative care development is a good success story in itself. A few success stories have been published in palliative care journals and also on non-profit sector websites (mainly for fundraising reasons).

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is no information available at this time.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

- It is hoped that palliative care units will become established in public hospitals and that services become available in most regions of the country.
- It is also hoped that palliative care is included in the curricula of Medical, Nursing and Social Science Faculties so that more physicians, nurses and social workers are available to provide palliative care services in the future.
- Integration of palliative care services at the regional level (according to the timeline of the action plan).
- Passing the law of palliative care in the Albanian Parliament.
- Increasing access to (and usage of) opioids for terminally-ill patients.
- Lobbying and advocacy initiatives to address the psychosocial issues facing palliative care patients and their families.
- Improved State and non-State organization of palliative care services.

Most significant issues facing hospice and palliative care in the next three years:

- Economic issues are the most important challenges to be faced. AAPC and the National Palliative Care Working Group play a very important role in the development of palliative care services throughout the country.
- International donors leaving Albania or reducing funds for palliative care services due to increased interest in the areas of policy and education.
- Parliamentary elections in the middle of 2013 may affect the process of developing a law relating to palliative care, and delay accomplishment of the National Strategy objectives.

Implications for palliative care relating to the current economic crisis:

- Reduction of funding from donors may result in the possible closure of existing centres and the interruption of palliative care development.
- Economic crises are affecting palliative care grants and fundraising opportunities within and outside the country.

References

Ryder Albania Association. "Training and Education Courses on Palliative Care with multidisciplinary staff working in Primary Health Care Service and with family members of the patients under assistance of Ryder Albania Association (RAA)".

Winslow M. 1999. "Opening Up. A first glimpse of life and death in Albania". *Wellcome news*, 19, Q2.

National Standards of Palliative Care have been developed and the Second National Palliative Care conference held in December 2010. A National Palliative Care Working Group has been established to develop a Strategic Plan for Palliative Care as part of the National Cancer Strategy

Andorra¹

NATIONAL ASSOCIATION/KEY PERSON

**Palliative Care Functional Unit,
Hospital Nostra Senyora de Meritxell**
*Unitat Funcional Interdisciplinàr Socio sanitària
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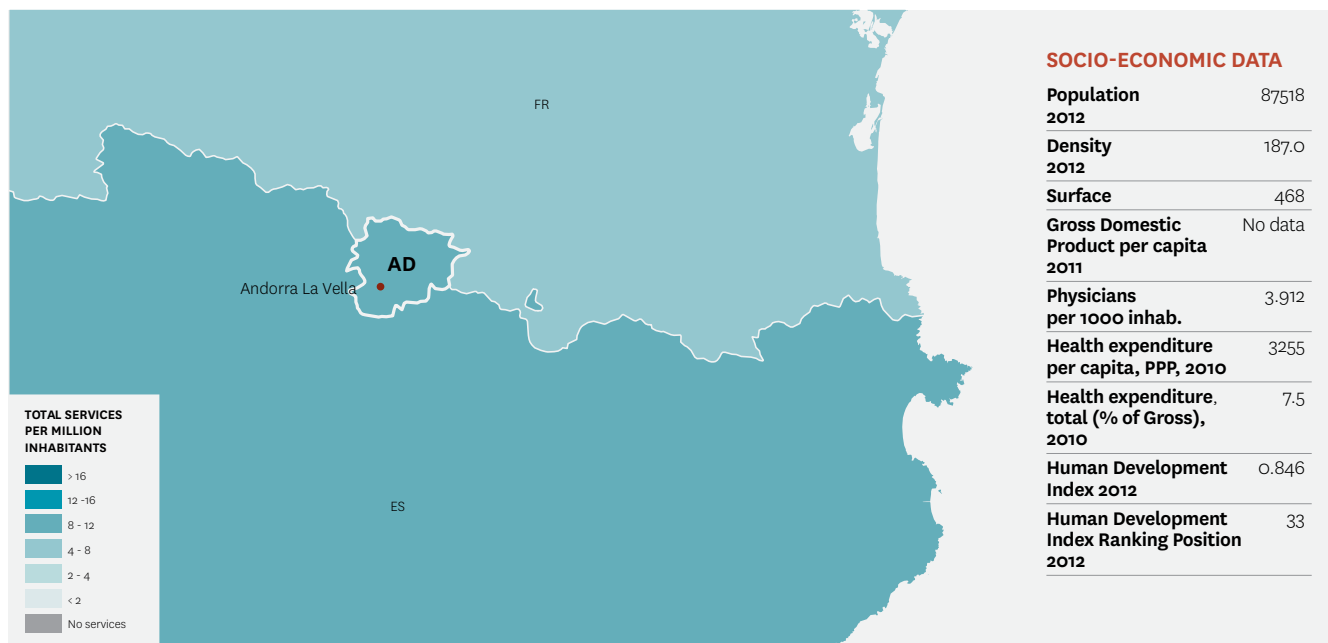
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KEY CONTACT

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | ○ |
| Hospital palliative care support team | 1(3-10) |
| Home palliative care support team | ○ |
| Mixed palliative care support team | ○ |
| Palliative care units in tertiary hospitals | ○ |
| Palliative care units in non-tertiary hospitals | ○ |
| Inpatient hospice | ○ |
| Day hospice/day care centre | ○ |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:
xlatorre@saas.ad

Additional comments:

There is no additional information available at this time.

Palliative care services for children:

There is no information available at this time.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

There is no information available at this time.

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

The formal creation of a palliative care support team in the Hospital of Andorra.

Overall progress in hospice and palliative care:

Has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: palliative care available for inpatients.
- Nursing homes: no development.
- Residential homes for the elderly: no development.
- Other community settings: community healthcare professionals are receiving training in palliative care.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

There has been no expansion from a focus on cancer patients to address the needs of 'non-cancer' patients.

Perceived barriers to the development of hospice and palliative care:

(i) Lack of global coordination (ii) lack of continuity of care between specialized services and other resources in the community.

Perceived opportunities for the development of hospice and palliative care:

(i) The fact that Andorra is a small country makes organization, continuity and coordination of palliative care easier (ii) there is a fluent relationship between healthcare professionals (iii) implementation of palliative care throughout the whole country is a priority of the health system contained in the National Strategy for Health.

Other issues relevant to the development of hospice and palliative care:

There is no information available at this time.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

There is no information available at this time.

Directory or catalogue of palliative care services:

There is no information available at this time.

Congresses, scientific meetings or scientific journals in palliative care:

There is no information available at this time.

Palliative care research capacity:

There is no information available at this time.

Palliative care collaboration:

There is a fluent relationship with professionals from the palliative care unit at the Catalanian Institute of Oncology in Spain. Healthcare professionals from Andorra have received training in palliative care there, and there is also a common language (Spanish and Catalan). A number of pioneer groups exist in Andorra. The initial development of these groups resulted as a consequence of the increased interest in palliative care in 2008 amongst some healthcare professionals (Esther Argiles and Xavier Latorre) and the creation of a new structure in the healthcare system. There has been an increased sensibility to this issue since 2007. The Minister of Health has received formal advice and consultation from the QUALY Study Centre of Hospitalet, Barcelona, Spain since 2009.

Worldwide palliative care alliance level of development:

3A (Isolated palliative care provision).

A palliative care support team in the Hospital of Andorra has been formally created to provide inpatient care and palliative care provision is to be integrated into community healthcare services in the country

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:
There is no information available at this time.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: There is no information available at this time.
- Nursing: There is no information available at this time.
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: There is no information available at this time.
- Nursing: There is no information available at this time.
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Translation of palliative care documents or other materials:
There is no information available at this time.

Initiatives to develop healthcare professional leadership in palliative care:
There is no information available at this time.

Officially recognized medical certification:

In Andorra, there is no School of Medicine or specialized training system. However, the Ministry of Health recognizes some forms of specialization from Spain and France. A number of palliative care professionals have received specialized training through a Masters Course undertaken in Catalonia, Spain.

Capacity of palliative care workforce training in Universities and Medical Schools:

There is no information available at this time

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:
There is free availability of essential medications.

Developments/opportunities/barriers relating to the accessibility of essential medications:
Essential medications are accessible (but only under special prescription).

Developments/opportunities/barriers relating to the affordability of essential medications:
There is no information available at this time.

Initiatives to change regulations that may restrict physician or patient access to pain relief:
There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':
There is no information available at this time.

Initiatives that examine access to opioid medication for economically disadvantaged persons:
There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:
There is no information available at this time.

A number of community healthcare professionals have received training in palliative care and there is a fluent training relationship with the palliative care unit at the Catalanian Institute of Oncology in Spain. There is free availability of essential medications

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

There is no information available at this time.

The impact of these policy changes and ways in which they have been important:

There is no information available at this time.

Development of a national palliative care consensus:

There is no information available at this time.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

There is no information available at this time.

Development of an advocacy framework for integrating palliative care into the health care system:

There is no information available at this time.

Strategies to improve political awareness and government recognition of palliative care:

After the design of an official strategy to improve political awareness and government recognition of palliative care there has been further promotion of the discipline by a number of healthcare professionals in Andorra.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

There is no information available at this time.

Involvement with the European Union in relation to hospice and palliative care initiatives:

There is no information available at this time.

Development of initiatives framing palliative care as a 'human right':

There is no information available at this time.

General legislation relating to palliative care:

There is no information available at this time.

Published national documents relating to palliative care standards and norms:

There are national documents relating to palliative care standards and norms in process. The provision of palliative care and its integration within the National Health System is described in a document promoted by the QUALY Study Centre of Hospitalet, Barcelona, Spain which was adopted by the Minister of Health and distributed to healthcare professionals.

National Plan or Strategy of Palliative Care:

A National Plan of Palliative Care is currently under construction.

National Cancer Control Strategy:

There is no information available at this time.

National HIV/AIDS Strategy:

There is no information available at this time.

National Primary Health Care Strategy:

Palliative care provision is to be integrated into community healthcare services in Andorra.

Designated policy maker for the delivery of palliative care services:

Josep M. Casals, Director General de Salut i Benestar, Ministeru de Salut i Benestar, salut@govern.ad.

Department of Health specific responsibility for the delivery of palliative care services:

Director General de Salut i Benestar, Ministeru de Salut i Benestar.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

A second special prescription for opioids is mandatory. Morphine is freely available and can be obtained from the pharmacy with this special prescription. There is no other legislation relating to opioids. In relation to pain guidelines, a Pain Management Protocol exists that is officially approved by the Commission of Hospital Therapeutics.

Funding of palliative care services:

Health Insurance is not freely available for all people; a partial payment may be required for palliative care consultation if a person has no health insurance. Partial payment may be required for hospitalisation and medications as well. Funding provided by the Health Insurance System is similar to the French model with a moderator ticket of 10% for hospitalization and 25% for external consultation and exploratory operations. However, persons with a chronic illness receive full remuneration of 100% - this is particularly the case with oncology patients and those receiving palliative care with any condition.

There are documents relating to palliative care standards and norms in process and a National Plan of Palliative Care is currently under construction. Implementation of palliative care throughout Andorra is a priority of the National Strategy for Health

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

There is no information available at this time.

Major public discussion, debate or controversy about hospice and palliative care:

There is no information available at this time.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

There is no information available at this time.

Hospice or palliative care 'success' stories:

There is no information available at this time.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is neither legislation nor public debate relating to euthanasia or assisted dying. This is possibly due to the fact that Andorra is a country that is under religious authority: the Catholic Bishop of Lérida exerts much influence in this area.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

The development of palliative care has started and cannot ever stop!

Most significant issues facing hospice and palliative care in the next three years:

There is no information available at this time.

Implications for palliative care relating to the current economic crisis:

There is no information available at this time.

References

There are no known publications at this time.

Armenia¹

NATIONAL ASSOCIATION/KEY CONTACT

Armenian Pain Control and Palliative Care Association (APC&PCA)

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Artashes Tadevosyan, VICE-PRESIDENT

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babakavetis@yahoo.com

N.B. Two key contacts completed the EAPC Facts Questionnaire and information from both of the questionnaires has been used in the compilation of this Country Report.

¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | ○ |
| Hospital palliative care support team | ○ |
| Home palliative care support team | 4 |
| Mixed palliative care support team | ○ |
| Palliative care units in tertiary hospitals | ○ |
| Palliative care units in non-tertiary hospitals | ○ |
| Inpatient hospice | ○ |
| Day hospice/day care centre | ○ |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Artashes Tadevosyan
- Avetis Babakhanyan

Additional comments:

- There is an ongoing pilot project jointly funded by the Global Fund, World Health Organization (WHO) and Open Society Foundation (OSF) in four sites across Armenia; two in Yerevan (capital city), and two in other regions - one in Vanadzor (3rd largest city in Armenia) and one in Ararat (a small town). There must be a minimum of 30 beneficiaries at each site (total 120 patients). The teams provide palliative care in the hospital as well as at home. Each team consists of five workers: physicians, nurses, social workers, and a psychologist. Doctors are anaesthesiologists, so care is mostly limited to pain management. Members of the team have monthly meetings to discuss common problems and present case studies.

- There are some NGOs called "hospice" that provide non-medical nursing services to elderly, post-stroke and other categories of patients. Nurses provide general care at home (not specifically palliative care) on a paid basis (approximately 30-50 Euros per day paid by the patients' relatives); there are no doctors or registered nurses working at these "hospices".
- Many hospitals and clinics provide 'some aspects' of palliative care by physicians and nurses with basic knowledge and training in the discipline. However, such services are mainly based on enthusiasm, and have limited effectiveness; hospitals also usually try to avoid caring for patients with a terminal illness (unless the patient/family are able to pay for the care provided) as death in hospital is considered as "negative" for their results.
- Patients get free consultations by a physician or a nurse at any hospital or polyclinic; the majority of healthcare professionals rarely ever refuse to provide any useful advice or support (including psychological support) if they are able to do so.
- It is unlikely that there will be volunteer palliative care services in Armenia at any time soon.
- Because palliative care is provided as part of general symptomatic care by any doctor (mostly oncologists), there is no specific or reliable data; the problem is that the majority of "palliative care providers" often don't possess the necessary skills or knowledge to really help those in need.

Palliative care services for children:

There is one home paediatric palliative care support team in Yerevan for 30 children funded since 2011 by Matra Foundation (Netherlands). There is also one mixed paediatric palliative care support team (although there are probably some other fragmented services provided by NGOs). There is only one paediatrician working in palliative care.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

- 2003** The Armenian Pain Control & Palliative Care Association is established (APC&PCA).
- 2004** APC&PCA marks the publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organization of palliative care) through meetings with public health authorities to explain that Armenia (as one of the consignees to the report) has to implement the recommendations' requirements and provisions. However, the Government position is that the document is merely a recommendation and does not have legislative status in Armenia.

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

A palliative care needs assessment has been conducted, there is an organized task force group on palliative care in the Ministry of Health, and a draft concept of palliative care has been developed and circulated amongst stakeholders according to local regulations. Drafts of new laws and amendments are in process relating to opioids and palliative care standards are currently being developed. A teaching centre in palliative care has been organized with the support of OSF. In 2011, the first 21 students were trained in pain management and opioid prescription. The pilot project is funded by Global Fund, WHO and OSF and has commenced at four sites in three regions of Armenia.

Overall progress in hospice and palliative care:

Palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: development in four sites – two in Yerevan (capital city), and two in other regions; one in Vanadzor (3rd largest Armenian city) and one in Ararat (a small town).
- Nursing homes: There is no information available at this time
- Residential homes for the elderly: There is no information available at this time
- Other community settings: There is no information available at this time.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

The Global fund pilot project aims to support patients with HIV/AIDS and TB but in reality the majority of patients have a cancer diagnosis and pain management is the most important component of care.

Perceived barriers to the development of hospice and palliative care:

(i) Lack of all resources – professional, financial - and facilities (ii) Legislative and administrative barriers (iii) Lack of public awareness.

Perceived opportunities for the development of hospice and palliative care:

(i) Currently, new Laws on Health Care are being developed in Armenia, which provides an opportunity to include palliative care provision in relevant legislation (ii) Education reforms stipulated within the Bologna Declaration have enabled palliative care curricula to be developed (but not yet implemented).

Other issues relevant to the development of hospice and palliative care:

There is no information available at this time.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- The Armenian Pain Control & Palliative Care Association (APC&PCA) (Hakacavain ev paliative khnamqi asociacia) was formed in 2003; there is a website (www.hakacav.am) but the association does not represent the whole country - mostly the capital Yerevan.
- There is a second national association of palliative care: Association Gayush (Asociacia Gayush), which was formed in 2009 and specializes in paediatric palliative care. The association has a website (www.gayush.am) but does not represent the whole country - mostly the capital Yerevan.

Directory or catalogue of palliative care services:

There is no directory or catalogue of palliative care services.

Congresses, scientific meetings or scientific journals in palliative care:

There are no congresses, scientific meetings or scientific journals in palliative care.

Palliative care research capacity:

There are a number of researchers in the area of palliative care: Artashes Tadevosyan (artashes.tadevosyan@meduni.am), Hrant Karapetyan (pallium@inbox.ru), and Ashot Gyulbudaghyan (ashot.gyulbudaghyan@yahoo.com).

Palliative care collaboration:

- An effective collaboration has been established with experienced palliative care specialists from Romania (Hospice Casa Sperantei (HCS)). Healthcare professionals from Armenia have visited HCS to attend theoretical and practical courses in palliative care. The Romanian model of palliative care development is very relevant to Armenia; it appears that both governmental and non-governmental organizations in Armenia are recommending that the Romanian model is adopted.
- Stephen Connor (Worldwide Palliative Care Alliance) and Mary Callaway (OSF) are actively engaged in palliative care coordination and development in Armenia, conducting a needs assessment and organizing training programs, etc.
- APC&PCA organizes seminars, advocacy campaigns, and presentations, and participates in international conferences. Two members of the association are members of the Ministry of Health Task Force to develop a concept paper on palliative care in Armenia. The Association has been very active in establishing palliative care in Armenia and raising awareness about the discipline; there has been much educational activity, including organization of training courses within Armenia (and also abroad) for practitioners interested in palliative care.

Worldwide palliative care alliance level of development:

3A (Isolated palliative care provision).

Laws on Health Care are being developed in Armenia, which include palliative care provision in relevant legislation. A pilot project to provide palliative care in the hospital and at home has commenced at four sites in three regions of Armenia

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

In 2011, a teaching centre was established which is run by APC&PCA. Currently, there is a 40-hour module in pain management and opioid prescription; soon EPEC-O training materials will be translated and adapted to Armenian needs. There is also organized training for nurses at an NGO relating to the protection of patients' rights and Yerevan State Medical University has applied for a grant to develop a curriculum in palliative care. In 2011, there were some fellowship visits organized by local NGOs (Western Professors were invited), and Romanian practitioners have visited Armenia to teach the principles of Methadone use.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: No development was reported.
- Nursing: No development was reported.
- Social work: No development was reported.
- Other professions: No development was reported.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: No development was reported.
- Nursing: No development was reported.
- Social work: No development was reported.
- Other professions: No development was reported.

Translation of palliative care documents or other materials:

The WHO document Ensuring Balance in National Policies on Controlled Substances: Guidance for availability and accessibility of controlled medicines has been translated in Armenian.

Initiatives to develop healthcare professional leadership in palliative care:

There is no information available at this time.

Officially recognized medical certification:

- There is no official certification. Technically, palliative care as it defined is not available in Armenia because there are no doctors trained as palliative care specialists. A curriculum on palliative care is not available at Yerevan State Medical University or the two private universities.
- The APC&PCA have developed a certificate in pain management and opioid prescription (although this awaits official confirmation by the Ministry of Health).

Capacity of palliative care workforce training in Universities and Medical Schools:

- There are three medical schools in Armenia. Yerevan State medical University provides graduate and post-graduate education and residency. There are two private universities (Armenian Medical University and Haybusak) that provide education to the Bachelor and Masters level.
- There are no palliative medicine professors of any kind; Narine Movsisyan is an Associate Professor in Anaesthesiology and Intensive Care at Yerevan State Medical University.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- Painkillers, antidepressants and anticonvulsants are available. However, the use of opioids is very limited due to restrictive regulations; oral and slow release forms of morphine are not available at all.
- Reform of legislation may provide an opportunity to make opioid regulations less restrictive and therefore increase availability; there is a need to register oral morphine and make it available.
- There is a need to extend the number of registered opioids in Armenia.

Developments/opportunities/barriers relating to the accessibility of essential medications:

Painkillers, antidepressants and anticonvulsants are accessible (opioids are not).

Developments/opportunities/barriers relating to the affordability of essential medications:

- Most medications are very expensive (especially patches).
- The introduction of co-payments reduced the affordability of all medications.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

None, but such initiatives are needed as current regulations are very restrictive.

Initiatives to promote attitudinal change in relation to 'opiophobia':

APC&PCA and a number of other NGOs held a few meetings, but there are not any systematic activities in this field.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

There have been a few presentations, meetings, and seminars, but they were not very structured or well organized.

A palliative care needs assessment has been conducted, there is a task force group on palliative care in the Ministry of Health, and palliative care standards are currently under construction

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

Definition of palliative care was included in draft of "RA Law on Health"; palliative care was officially recognized as a form of medical care (government order #1381-N, 03.12.2009); palliative care was included in the list of medical specialties (March 2011); official requirements for equipment and conditions of delivery of palliative care were established in 2011 (government order #175-N, 24.02.2011); standards on palliative care were drafted in 2011.

The impact of these policy changes and ways in which they have been important:

As a result of these legal and policy changes, Yerevan State Medical University has been able to commence work on curricula relating to the specialization of palliative care. Yerevan State Medical University (which provides education for psychologists) and a number of leading European Universities applied for an EU grant for curricula development at Bachelor and Masters Levels. NGOs and other associations have developed a legal base for activities relating to the provision of palliative care services.

Development of a national palliative care consensus:

The number of NGOs and other associations involved in palliative care has increased since 2006, and several joint seminars and meetings have been held in the capital and other regions. A draft on palliative care standards has been developed.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

APC&PCA had meetings with MPs, and officials of the Ministry of Health and Police. An NGO protecting patient's rights has been involved in similar activities.

Development of an advocacy framework for integrating palliative care into the health care system:

There is no information available at this time.

Strategies to improve political awareness and government recognition of palliative care:

There is no information available at this time.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

A pilot project providing palliative care for patients with HIV/AIDS and TB has been funded by the Global Fund; OSF has funded a teaching centre for training and re-training physicians; there has been improvement in the provision of palliative care for children with life-limiting illnesses in Yerevan funded by Embassy of Netherlands, project "Matra"; there is an ongoing "Stop the Pain" campaign funded by Human Rights Watch.

Involvement with the European Union in relation to hospice and palliative care initiatives:

Yerevan State Medical University, together with nine European universities applied for a TEMPUS grant to develop a curriculum in palliative care in 2011. The NGO protecting patient's rights organized training of nurses in Romania in 2011.

Development of initiatives framing palliative care as a 'human right':

There is no information available at this time.

General legislation relating to palliative care:

Palliative care legislation is in process in Armenia: a definition of palliative care is included in the draft law on public health; the discipline was officially recognized as a form of medical care in December 2009, and included in the list of medical specialties in March 2011.

Published national documents relating to palliative care standards and norms:

Draft standards of palliative care were published in February 2012. The standards were developed for the Ministry of Health by the Patients' Rights Protection Center and the Palliative Care Working Group of the APC&PCA (funded by the Global Fund).

National Plan or Strategy of Palliative Care:

There is a National Strategy of Palliative Care in progress: the concept paper on palliative care is in circulation and under discussion at the Ministry of Health.

National Cancer Control Strategy:

There is no National Cancer Control Strategy.

National HIV/AIDS Strategy:

There is discussion about a National HIV/AIDS Strategy between all key stakeholders; provision of palliative care will be included in a draft of the strategy.

National Primary Health Care Strategy:

The National Primary Healthcare Strategy does not contain an explicit reference to palliative care provision.

Designated policy maker for the delivery of palliative care services:

There is no designated policy maker for the delivery of palliative care services.

Department of Health specific responsibility for the delivery of palliative care services:

The Department of Health does not have specific responsibility for the delivery of palliative care services (Chief of staff of Ministry of Health is Mr. Suren Krmyan).

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There are no systems of auditing, evaluation or quality assurance that monitor the standard of palliative care.

Opioid legislation/Pain guidelines:

A district oncologist can prescribe injectable morphine (other forms are not available) for outpatients only but there is a maximum daily dose. Initial prescription must be approved by a committee comprising of three physicians including the deputy head of the polyclinic and a Police representative; any changes in dosage must be approved by the committee. The prescription must be signed by an oncologist and has three stamps and seals. A prescription can only be for a two-day supply (three days at weekend). Medication is provided free of charge. There is only one specialised pharmacy in Yerevan and pharmacies in the central regional hospitals. If the patient's relative is designated to collect the medication from a pharmacy, they have to get permission from the Police. New legislation relating to opioids is currently being drafted which will allow all doctors to prescribe opioids (but with the same restrictions). There are "Cancer pain management guidelines" (a printed version).

Funding of palliative care services:

- There is no formal payment for palliative care consultation. The patients or their relatives do not pay for any palliative care services. In most cases such payments are not regulated by any legal or moral principles.
- General hospitalization (not palliative care) requires full payment by the majority of patients; partial payment or free hospitalization may be applicable for certain groups of patients (poverty, disability, etc.)
- In general, the vast majority of patients pay full price for all medications (not palliative care) which are purchased from a pharmacy; partial or no payment may be applicable for certain groups of patients (poverty, disability, etc.); all opioids for palliative care patients are free of charge.
- Informal payments still play a significant role in health care in Armenia. It should be acknowledged that the average salary in Armenia in 2010 was 102 thousand dram (approximately 200 EUR) yet in the health care sector it was just 68 thousand dram (approximately 130 EUR) (Morphine costs \$15-20).

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:
There is no objective data but it appears that people have become more familiar with the idea of “hospice/palliative care”. A survey is planned with MPH students to reveal levels of public awareness about these terms.

Major public discussion, debate or controversy about hospice and palliative care:

There has not been much discussion, debate or controversy about hospice and palliative care, although there was a talk show on TV about euthanasia and palliative care which involved the participation of the President of APC&PCA.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

Several NGOs (main one is OSF Armenia) launched a campaign “Life without pain” with some media activity and a website (www.stopthepain.am).

Hospice or palliative care ‘success’ stories:

There is no information available at this time.

Initiatives seeking the legalisation of euthanasia or assisted dying:

Euthanasia is illegal in Armenia - the only initiative has been the talk show mentioned above.

Drafts of new laws and amendments are in process relating to opioids and a centre has been opened to provide training in pain management and opioid prescription. Education reforms have enabled palliative care curricula to be developed

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

The Ministry of Health plan to open a 10-bed palliative care department in the National Oncology Centre in 2012. If Yerevan State Medical University succeeds in the TEMPUS grant application, they will develop curricula in palliative care and encourage Universities to organize clinics for bedside training of students in each department.

Most significant issues facing hospice and palliative care in the next three years:

It is hoped that the MoH will be consistent in their actions and that the first palliative care wards will be officially opened in the Oncology Centre. After successful completion of the Global Fund pilot project, more interest is expected from State officials relating to the issue of palliative care. APC&PCA is at the centre of all these activities and is involved in both education and advocacy processes. APC&PCA is also a TEMPUS grant consortium member. Both APC&PCA and Yerevan State Medical University can play a key role in the development of palliative care in Armenia.

Implications for palliative care relating to the current economic crisis:

Funding is the biggest problem facing palliative care development in Armenia; there is a lack of state funds, an absence of private businesses support, weaknesses in local benevolent organizations and charities, and poor traditions in volunteering.

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Austria¹

NATIONAL ASSOCIATION

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Additional information provided by:

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|--|-----------------------|
| Volunteer hospice team | 146 |
| Hospital palliative care support team | 20 (n/a) |
| Home palliative care support team | 40 |
| Mixed palliative care support team | 18 |
| Palliative care units in tertiary hospitals | 29 (254) |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 8 (68) |
| Day hospice/day care centre | 3 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

Annual data collection of Hospice Austria: Austrian data survey 2011 - see www.hospiz.at. A questionnaire was sent to all hospice and palliative care institutions in Austria. The return rate with regards to participating institutions is nearly 100% and with regards to certain data ranges from 70% to 100%.

Additional comments:

- In 2011, Austria had 3,266 volunteers; 88.5% of them female, 11.5% male. They cared for 10,052 patients and spent 235,266 hours with the patients and their families. Volunteers contributed an additional 126,226 hours for fundraising, advanced training, and administrative help.

- The number of beds relating to Hospital palliative care support team includes all the hospital beds that a team is responsible for (which are usually all the beds in a hospital) and also the beds that the mixed palliative care support teams are responsible for. Two of 19 teams provide support for three hospitals, six teams for two hospitals and the rest for one hospital.
- The Home palliative care support team in Austria usually comprises of employed palliative care nurses and (mostly part-time) physicians. In some teams, all staff except nurses work on contracts based on demand.
- There are 18 Mixed palliative care support teams: 12 in Lower Austria, five in Styria, and one in Carinthia. For the number of beds see Hospital palliative care support team.
- Palliative care units receive almost 100 % public funding throughout Austria.
- Austria has only two freestanding inpatient hospices (at Salzburg and Graz); the other six are hospice wards integrated in nursing homes in Lower Austria.
- Day hospices are in Vienna, Graz and Salzburg. They are usually open between one and four days each week.

Palliative care services for children:

There are some paediatric volunteer hospice teams: two mobile paediatric palliative care teams and one paediatric hospital palliative care support team in St. Anna's Childrens Hospital. In 2012, a task force chaired by the Austrian Health Institute (Gesundheit Österreich – GÖG) and Hospice Austria developed a master plan for hospice and palliative care for children and young people in Austria, suggesting structures and defining quality of care.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

- 1989** First mobile hospice and palliative care team commences in Vienna.
- 1992** First inpatient hospice opens in Vienna.
- 1993** Hospice Austria, the umbrella organization of the Austrian hospice and palliative care services, is founded by Hildegard Teuschl.
- 1997** A minimum of 60 hours of "Palliative Care" is integrated into the curriculum of the undergraduate education for registered nurses.
- 1998** First multidisciplinary course for palliative care commences in Vienna
- 1999** Palliative care units become part of the national plan for acute hospitals in Austria.
- 2001** All political parties in Austria vote against euthanasia and for the further development of hospice and palliative care.
- 2001** First Austrian-wide curriculum for volunteers in hospice and palliative care.
- 2003** Hospice Austria, the umbrella organization of the Austrian hospice and palliative care services, develops a clear perspective for the further development of hospice and palliative care.
- 2003** The first palliative care facilities are implemented in a medical university in Austria (Graz).
- 2003** "Declaration of the Austrian Government 2003 to 2006" aims for fair access to hospice and palliative care services for all those who need it.
- 2004** The Austrian Palliative Care Association marks the publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organization of palliative care) with widespread discussion about the report among experts in hospice and palliative care. The Minister of Health and the State Secretary are informed about the report, and Dr. Harald Retschitzegger, an Austrian physician, is a member of the working group.
- 2004** The document "Abgestufte Hospiz- und Palliativversorgung in Österreich, Graded Hospice and Palliative Care in Austria" (ÖBIG, Vienna) is published by the by Austrian Institute of Health.
- 2005** The document "Artikel 15 a Vereinbarung über die Organisation und Entwicklung des Gesundheitswesens" (p 8, Article 3 (2), Vienna) is published.
- 2005** The Ministry of Health implements a working group to prepare recommendations for the stepwise integration of hospice and palliative care into the health care system in Austria.

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- The plan of graded hospice and palliative care has been integrated into the National Health Care Plan of Austria. This will speed up its implementation which is currently approximately 50% complete. Development of hospice and palliative care is monitored by a yearly audit of all providers by Hospice Austria. The plan has been almost fully implemented in one county in Austria (all aspects of hospice and palliative care within the context of mandatory national health care insurance are available, but more services are still needed);
- Recommendations for the quality for all services of graded hospice and palliative care have been developed which cover quality of structure and quality of processes. A manual for all services with the key processes has been published;
- All medical universities in Austria have palliative care as a mandatory part of their curricula. The position of a full professor in palliative care has been established at the largest medical university in Austria (Medical University of Vienna). A multi-professional Masters course for palliative care has been established at the Medical University of Salzburg in co-operation with Hospice Austria and St. Virgil. IFF in Vienna organises a multi-professional Master's course for palliative care and has implemented a PhD Program for palliative care also.

Overall progress in hospice and palliative care:

Hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: This is the most developed part of the system with approximately 78% palliative care coverage (palliative care units). Hospital Palliative Care Support Teams are less widespread and achieve coverage of approximately 31%.
- Nursing homes: There is approximately 20% palliative care coverage in nursing homes and residential homes for the elderly. Since 2005, Hospice Austria (the umbrella organisation of approximately 260 hospice and palliative care organisations in Austria), has been considering how to integrate hospice and palliative care in nursing homes; a taskforce has been formed including all relevant partners in the field to develop and define standards of quality. In 2008, the Austrian standards for hospice and palliative care in nursing homes were finalized and are now the foundation of any work in this area. The hospice movement in Vorarlberg started the implementation in 12 model homes in 2004 after a survey commissioned by the federal state had shown gaps in this area. Lower Austria started in 2009 with eight model homes and Styria in 2010 with six model homes. Vienna, Burgenland and Salzburg started in 2012. Hospice Austria initiated the development of a curriculum in Palliative Geriatrics. The goal of the project 'Hospice and Palliative Care in Nursing Homes' (developed by Hospice Austria) is to ensure sustainable and competent hospice and palliative care in all Austrian nursing homes. In 2009, an Austrian advisory board for Hospice and Palliative Care in Nursing Homes was founded. It enables cooperation between Hospice Austria, the Ministry of Health and Ministry of Social Affairs, the Austrian Medical Association, the national organization of nursing homes, the GÖG/ÖBIG (Austrian Health Institute), the Main Association of Austrian Social Security Institutions and ÖGAM (Association of General Practitioners in Austria). The initial project of Hospice Austria was possible due to funding by Fonds Gesundes Österreich. (<http://www.hospiz.at/>)
- Residential homes for the elderly: These are the same structure as "nursing homes".
- Other community settings: There is approximately 70% palliative care coverage provided by volunteer hospice and home palliative care support teams.

Graded palliative care has been integrated into the National Health Care Plan of Austria. There is increased awareness of the need for palliative care in nursing homes, a plan for a children's hospice and palliative care standards are being developed

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

About 20 % of the patients are non-cancer patients, There has also been an increased focus on dementia.

Perceived barriers to the development of hospice and palliative care:

Finance and structures for palliative care in the Austrian Health and social care system; awareness of palliative care; education in palliative care.

Perceived opportunities for the development of hospice and palliative care:

Structured development through the established National Health Plan; improved education in medical universities and other teaching institutions, Master Courses in palliative care; increased awareness of the need for palliative care in nursing homes, a master plan for children's hospice and palliative care with quality standards.

Other issues relevant to the development of hospice and palliative care:

There is no information available at this time.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- There are two national palliative care associations in Austria that are both equal partners in the development of the discipline:
- Hospice Austria (Hospiz Österreich - Dachverband von Palliativ- und Hospizeinrichtungen) was formed in 1993; it is representative of the whole country and has a website (www.hospiz.at).
- Another national association, the Austrian Palliative Care Association (Österreichische Palliativ Gesellschaft), was formed in 1998; it is also representative of the whole country and has a website (www.palliativ.at).

Directory or catalogue of palliative care services:

There is a printed version that provides contact data of hospice and palliative care institutions in Austria by Hospice Austria: Hospiz- und Palliativführer Österreich (First edition 2002/latest edition 2008). At the website, there is an annually updated directory organised by federal states (www.hospiz.at).

Congresses, scientific meetings or scientific journals in palliative care:

- The Austrian Palliative Care Association has a congress every two years attended by approximately 200 people;
- The symposium IFF ÖRK is held every two years and is attended by approximately 300 people;
- There is an annual World Hospice and Palliative Care Conference hosted by Hospice Austria which is attended by approximately 100 people;
- There are many meetings at the local and regional level throughout Austria;
- Professor Andreas Heller (IFF Wien) is the editor of the journal Praxis Palliative Care (published in collaboration with Germany and Switzerland). The German publication Palliativ Medizin contains two pages on palliative care development in Austria (four times per year).

Recommendations for the quality for all services of graded hospice and palliative care have been developed which cover quality of structure and quality of processes. A manual for all services with the key processes has been published

Palliative care research capacity:

- There are a number of university professors working in palliative care: Dr. Herbert Watzke (Division of Palliative Care, Medical University of Vienna); Dr. Hellmut Samonigg (Palliative care unit, Medical University of Graz); Dr. Andreas Heller (IFF - Abteilung Palliative Care und Organisationsethik); Dr. Katharina Heimerl (IFF - Abteilung Palliative Care und Organisationsethik); (PMU Paracelsus private medical university, Paracelsus Medizinische Privatuniversität runs a programme for Master of Palliative Care, where all participants write a Master Thesis, MSc.).
- There are also a number of other researchers in palliative care: Assistant Professor Dr. Elisabeth Reitingner; Professor Dr. Sabine Pleschberger; Assistant Professor Dr. Thomas Krobath; Assistant Professor Dr. Doris Lindner; Dr. Erich Lehner; Dr. Jürgen Osterbrink; Patrick Schuchter; Mag.a Elisabeth Wappelshammer; Mag. Klaus Wegleitner; Mag.a Claudia Wenzel, Dr. Dietmar Weixler, MSc.

Palliative care collaboration:

- The board of Hospice Austria has members from all nine federal hospice and palliative care institutions in Austria; a lot of networking and coordination is therefore possible. Different institutions cooperate with each other and learn from each other, e.g. Volunteer Hospice teams and Home Palliative Care Support teams, palliative care units, inpatient hospices, day hospices.
- There is collaboration on the Master programme in palliative care between Hospice Austria, Paracelsus Private Medical University in Salzburg and the Conference Centre St. Virgil. Different providers of palliative care courses in Germany are also linked to the Master programme (their graduates can study in Austria; German palliative care professors are teachers on the programme);
- Hospice Austria cooperates with different national organisations: for example, Help the Hospices.
- Universities (PMU and IFF) cooperate with universities abroad: for example University of Freiburg in Germany, Justig, Liebig University Giessen (Germany), Lancaster University (UK) and also in the management of the "European Task Force for Palliative Care in Long Term Care Homes".
- There is collaboration on research workshops: for example, New Housing Models for people with Dementia towards the End-of-life. International Workshop funded by the European Science Foundation, Vienna (December 1st – December 3rd 2011). The Workshop brought together European research expertise on new housing models for people with dementia and end-of-life care for older people.
- World Hospice and Palliative Care Day events are hosted by Hospice Austria and the hospice and palliative care organizations in the federal states and vary from year to year.
- Palliative care pioneers include: Hospice Austria, the Austrian Palliative Care Association, Caritas and Caritas Socialis. In all federal states of Austria, the first hospice and palliative care services were initiated in the late 1980s and throughout the 1990s; 1987 saw the founding of IGSL by Dr. Erich Aigner; a major step in development was the founding of Hospice Austria in 1993 by Sr. Mag. Hildegard Teuschl CS; in 1998 the Austrian Palliative Care Association was founded by Dr. Michaela Werni-Kourik and Dr. Franz Zdrahal; Caritas and Caritas Socialis provided the first hospice and palliative care services in Vienna.

Worldwide palliative care alliance level of development:

4B (Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- All medical universities in Austria have palliative care as a mandatory part of their curricula;
- The position of full professor of palliative care has been established at the largest medical university in Austria (Medical University of Vienna);
- A multi-professional Masters course in Palliative Care has been established at the Paracelsus Private Medical University of Salzburg and IFF in Vienna.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: All medical universities in Austria have palliative care as a mandatory part of their curricula; the position of a full professor of palliative care has been established at the largest medical university in Austria (Medical University of Vienna);
- Nursing: The basic training of nurses comprises of palliative care
- Social work: n/a
- Other professions: n/a

Specific developments in post-graduate palliative care education initiatives:

- Medicine: A multi-professional Masters course in palliative care has been established at the Paracelsus Private Medical University at Salzburg; post-graduate courses in palliative medicine are offered yearly by the Austrian Palliative Care Association;
- Nursing: A multi-professional Masters course in palliative care has been established at the Paracelsus Private Medical University at Salzburg;
- Social work: A multi-professional Masters course in palliative care has been established at the Paracelsus Private Medical University at Salzburg;
- Other professions: A multi-professional Masters course in palliative care has been established at the Paracelsus Private Medical University of Salzburg. IFF offers a multi-professional Master's Program and PhD – Program in Palliative Care.

Translation of palliative care documents or other materials:

Some of the documents used for "Hospice and Palliative Care in Austrian Nursing Homes" have been translated into English and Hungarian. There has been no other translation of palliative care documents or other materials.

Initiatives to develop healthcare professional leadership in palliative care:

At the Master Program at Paracelsus Medical Private University (organised in co-operation with Hospice Austria and St. Virgil), leadership in palliative care is one of the major focuses.

Officially recognized medical certification:

- There is no official certification but a Master of Palliative Care (MSc.) is provided by Universitätslehrgang Palliative Care with three co-partners: Paracelsus private Medical University, Hospice Austria and St. Virgil Conference Centre; it is a three-level Masters programme with 92.5 ECTS. This form of accreditation was officially recognized in 2006. There are approximately 80 people with the academic title Akademische Palliativexperte and 40 people that have graduated with the MSc (Palliative Care). Another Master of Palliative Care is provided by IFF. At Level One for both Master programmes is a multi-professional basic palliative care course of 160 hours duration offered by 11 institutions throughout Austria. Almost 3,000 people have received qualifications from these courses. At Level Two of the Universitätslehrgang Palliative Care there are four different courses for 'special palliative care' of 160 hours duration each: there have been 87 graduates (medicine), 111 graduates (nursing), 51 graduates (psychosocial) and 130 graduates (paediatrics). At Level Three it is possible to graduate either with an academic title: academic palliative care expert (60 graduates) or MSc (Palliative Care) (80 graduates). Currently, there are approximately 50 people studying at this level. On both Master programmes there are many lecturers who teach palliative care; on Level One there are approximately 100 and on Levels Two and Three there are approximately 80.
- The "Diploma in Palliative Medicine" was established by the General Medical Council of Austria in 2007. The diploma course comprises of 68 hours of lectures and interactive sessions and teaches basic knowledge in Palliative Medicine.
- There is accreditation in process as there are ongoing negotiations to establish a specialisation in Palliative Medicine between the Austrian Palliative Care Association, the Federal Ministry of Health and the General Medical Council. The "Diploma in Special Palliative Medicine" is a prior step to the development and implementation of a skill-based accreditation process in Palliative Medicine.

Capacity of palliative care workforce training in Universities and Medical Schools:

- Austria has four medical schools: in three of those schools palliative medicine is a mandatory component; in one school it is optional.
- There is one full professor of palliative care; one full professor of palliative care (non-medical); one assistant professor of palliative care (non-medical); and approximately three "other professors" of palliative care (non-medical).

All medical universities in Austria have palliative care as a mandatory part of their curricula. The position of a full professor in palliative care has been established at the largest medical university in Austria (Medical University of Vienna).

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

The availability of essential medications is not a problem in Austria.

Developments/opportunities/barriers relating to the accessibility of essential medications:

The accessibility of essential medications is not a problem in Austria.

Developments/opportunities/barriers relating to the affordability of essential medications:

The affordability of essential medications is not a problem in Austria.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

There is no information available at this time.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

The plan of graded hospice and palliative care has been integrated into the National Health Care Plan of Austria; this will speed up its implementation which is currently at a level of 50%. Furthermore, by the end of 2012 hospice care (Inpatient Hospices, Day Hospices, Volunteer Hospice teams and Hospice care in Nursing homes) was integrated within suggestions about how to reorganize the field of care and the funding provided by the Ministry of Social Affairs.

The impact of these policy changes and ways in which they have been important:

The government will have to take responsibility for the costs of institutional palliative care (wards, hospices, day care centres) and ambulatory palliative care (mobile palliative and volunteer hospice teams) in the future.

Development of a national palliative care consensus:

There is a National Development Plan for Palliative Care; there are National standards of Palliative Care that structure all elements of this plan; there is a National manual for the key-processes of hospice and palliative care.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

There was a meeting in the House of Parliament (organized by Hospice Austria) involving members of all organizations responsible for health care in 2012 (another is due in spring 2013).

Development of an advocacy framework for integrating palliative care into the health care system:

There is no information available at this time.

Strategies to improve political awareness and government recognition of palliative care:

Hospice Austria is continuously working with Ministries and other relevant institutions in order to speed up implementation of the national hospice and palliative care plan. The next step will be a meeting and conference about hospice and palliative care in the House of Parliament in Spring 2013.

A multi-professional Masters course for palliative care has been established at the Medical University of Salzburg in co-operation with Hospice Austria and St. Virgil. IFF in Vienna organises a multi-professional Master's course for palliative care and has implemented a PhD Program for palliative care also.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

There is no information available at this time.

Involvement with the European Union in relation to hospice and palliative care initiatives:

Hospice Austria is a partner in two EC-Projects concerning Hospice and Palliative Care in nursing homes.

Development of initiatives framing palliative care as a 'human right':

This topic has been raised in several press conferences at scientific and other meetings.

General legislation relating to palliative care:

Austria has had a law relating to "Living Wills" since 2006 (Patientenverfügungsgesetz) and a Law relating to "family hospice leave" (Familienhospizkarenz) which enables relatives to care for palliative care patients or seriously-ill children for up to six months.

Published national documents relating to palliative care standards and norms:

- There is a printed version (Abgestufte Hospiz- und Palliativversorgung) (Graded Hospice and Palliative Care Plan) edited by the Austrian Federal Health Institute that includes criteria for structure and quality. It was first published in 2006, revised in 2012 and will be published again in 2013 (also available as a PDF at www.hospiz.at);
- Many different documents relating to palliative care standards have been produced by Hospice Austria since 2000, e.g. for volunteers, nursing homes, social workers, nurses, etc. (available as PDFs at www.hospiz.at);
- A new manual for quality of processes in hospice and palliative care was published in 2012 by the Austrian Ministry of Health, edited by the Federal Health Institute, Hospice Austria and the Austrian Palliative Care Association (available as a PDF at www.bmg.gv.at).

National Plan or Strategy of Palliative Care:

There is a National Plan of Palliative Care: Abgestufte Hospiz und Palliativversorgung (2004) (Graded hospice and palliative care plan). All federal states also have their own hospice and palliative care plans.

National Cancer Control Strategy:

The document is currently being processed and will be published in 2012 (it includes the provision of palliative care).

National HIV/AIDS Strategy:

There is no National HIV/AIDS Strategy.

National Primary Health Care Strategy:

There is a federal plan for the development of palliative care services in Austria which has been in place since 2004. About half of the services mentioned in the plan have been implemented since that date. The plan was introduced into the official framework of mandatory health care services in Austria in 2010; this will speed up the implementation of palliative care in the various regions of Austria where services do not currently exist.

Designated policy maker for the delivery of palliative care services:

The need to develop hospice and palliative care services is mentioned in the government program. There is also a document entitled "15 a Vereinbarung" which regulates cooperation between national and federal states. This document states that hospice and palliative care should be implemented with high priority.

Department of Health specific responsibility for the delivery of palliative care services:

- There is no person in the government who has specific responsibility for the delivery of palliative care services. A problem is that there has been a lack of clarification about whether hospice and palliative care is part of the health care system or part of the social care system; as it belongs to both systems it is difficult to finance the services (especially inpatient hospices). Palliative care units are defined as a part of the health care system and their financing is secured. There is uncertainty about how the suggested implication of hospice care in the Pflegefonds (funding of care) is put into practice.
- The provision of health services (including palliative care services) in Austria is primarily the responsibility of the nine federal states and therefore varies from state to state. Styria is the only federal state that has public funding for all six types of hospice and palliative care services.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

- Hospice Austria conducts an annual data survey covering all hospice and palliative care institutions in Austria;
- The criteria for structure and quality in palliative care services are vital for gaining access to public funding;
- A manual to ensure the quality of processes within hospice and palliative care institutions was published in 2012; it was developed by Gesundheit Österreich/ÖBIG (Austrian Federal Health Institute), Hospice Austria and the Austrian Association of Palliative Care (with support of hospice and palliative care institutions). All services were invited to take part in this process which took five years to complete.

Opioid legislation/Pain guidelines:

- Any physician is allowed to sign opioid prescriptions; prescriptions are specifically labelled and copies need to be made and stored. Opioids are available in all pharmacies and hospitals and can be obtained without a special visa.
- There are printed guidelines on pain management.

Funding of palliative care services:

- There is no payment for palliative care consultations;
- There may be a partial payment for hospitalization (10 Euros per day);
- There may be a partial payment for some medications.

Austria has had a law relating to "Living Wills" since 2006 (Patientenverfügungsgesetz) and a Law relating to "family hospice leave" (Familienhospizkarenz) which enables relatives to care for palliative care patients or seriously-ill children for up to six months

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:
Public awareness or perception of hospice and palliative care has increased slightly.

Major public discussion, debate or controversy about hospice and palliative care:
There is no information available at this time.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:
There is no information available at this time.

Hospice or palliative care 'success' stories:
There is no information available at this time.

Initiatives seeking the legalisation of euthanasia or assisted dying:
The issue of euthanasia or assisted dying is increasingly discussed in the media (TV, press and cinema) and social forums.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:
Austria has made good progress along a structured line of development. New patient groups like children and elderly people (especially those suffering from dementia) are well provided for.

Most significant issues facing hospice and palliative care in the next three years:
Pressure from the EC to legalize physician-assisted suicide; this topic needs to be carefully addressed in public and politicians have to be urged not to change the current law in Austria.

Implications for palliative care relating to the current economic crisis:
Development of the national plan may slow down; great efforts are needed to increase awareness about palliative care issues.

Austria has made good progress along a structured line of development. New patient groups like children and elderly people (especially those suffering from dementia) are well provided for

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Azerbaijan¹

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 0 |
| Home palliative care support team | 0 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 0 |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 0 |
| Day hospice/day care centre | 2 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:
Gulara Afandiyeva.

Additional comments:

- It is impossible to count the actual number of services because there are no statistics relating to them.
- There are two day hospices: the AIDS Center which commenced in 2006; and the Sumqayıt Cancer Clinic which opened in 2012.

Palliative care services for children:

There is no information available at this time.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

Azerbaijan did not provide any information for the EAPC Atlas of Palliative Care in Europe (2007).

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- A palliative care needs assessment for the republic of Azerbaijan was undertaken in May 2007, supported by the International Palliative Care Initiative, Public Health Program, Open Society Institute (OSI);
- In 2008, a National Palliative Care Task Force was established represented by experts from different organizations and international consultants to formulate a set of policy documents for palliative care development and implementation in Azerbaijan;
- In 2009, one chapter (Palliative care and Human rights) of the Resource Guide "Health and Human rights" was translated from English to Azeri. This Resource Guide was edited and compiled by Jonathan Cohen, Project Director of the Open Society Institute (OSI) Law and Health Initiative, Tamar Ezer, Program Officer in the Law and Health Initiative, Paul McAdams, Senior Education Specialist at Equitas – International Centre for Human Rights Education - and Minda Miloff, consultant to Equitas;
- In 2009, the textbook "Methodological Guidelines on the Organization of Palliative Care in Azerbaijan" was prepared by the Working Group on Palliative Care and PhD expert Gulara Afandiyeva; the book was recommended to be used as a basic source for educating the civil sector about palliative care;
- In 2010, the concept of palliative care was included into the "Law of Azerbaijan Republic on Social Services" and also the "AIDS Law";
- In 2010, palliative care became a part of the pre- and post-diploma curricula of physicians, social workers and psychologists at Azerbaijan Medical University, Azerbaijan State Advanced Training Institute for Doctors and Baku State University;
- A number of pilot projects were initiated in Azerbaijan in 2010 by OSI: two projects at the state hospitals (Sumqayit Inter-regional Cancer Clinic and AIDS Center of Ministry of Health of Azerbaijan Republic) and six pilot projects implemented by NGOs (in Sumqayit and Baku cities and Lenkoran, and Hacıqabul regions). A number of projects implemented by civil sector representatives are planned in the "frameworks of social order" from the Ministry of Health by the Global Fund project.
- In 2011, the "Methodological Guidelines on the Organization of Palliative Care in Azerbaijan" was published.

Overall progress in hospice and palliative care:

Hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: There are two day hospices: the AIDS Center which commenced in 2006; and the Sumqayit Cancer Clinic which opened in 2012.
- Nursing homes: No improvement.
- Residential homes for the elderly: No improvement.
- Other community settings: No improvement.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

A few non-governmental organizations run projects that address the social and emotional problems of people with a terminal illness. The Jewish Organization "HAVVA", in conjunction with the Azerbaijan Psychologist Association (APA) provides training courses for oncologists relating to the psychological problems of terminally-ill patients and how to communicate with them. The psychologists help people diagnosed with Stage IV cancer deal with the issue of death and provide emotional support to the patient and their relatives. Palliative care projects, supported by the Ministry of Health of Azerbaijan Republic within the framework of the Global Fund Project and in conjunction with OSI, are fully committed to HIV/AIDS patients; one project assists TB patients infected with HIV in a TB hospital in the Buzovna district. The State Council support NGOs by financing activities related to palliative care services for cancer patients.

Perceived barriers to the development of hospice and palliative care:

- Low level of support from the Government. There is an absence of a model of social order and subsequently an absence of developed forms of cooperation between the State and the non-governmental sector;
- Palliative care is not built into the structure of the social services system and is not integrated into the health care system either;
- Lack of media information;
- A poor attitude on behalf of government officials and the general population towards palliative care as a human rights issue.

Perceived opportunities for the development of hospice and palliative care:

- Legislation: the organization of hospice care as a special field of the healthcare system should be approved by decision makers at the governmental level;
- Existing State and NGO sector pilot projects: there is strong support from the international palliative care organizations for the development of palliative care in Azerbaijan. This should include the organization of special training and study tours for relevant healthcare professionals;
- Development of special media programs on palliative care.

Other issues relevant to the development of hospice and palliative care:

There is no information available at this time.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

There is no information available at this time.

Directory or catalogue of palliative care services:

There is no information available at this time.

Congresses, scientific meetings or scientific journals in palliative care:

- The congress "Palliative Care Needs Assessment for the Republic of Azerbaijan" was held in May, 2007.
- A workshop-presentation "Methodological Guidelines on the Organization of Palliative Care in Azerbaijan" was held in 2011; approximately 40-50 people attended the workshop which is due to be held every four years.

There is palliative care provision at two day hospices in State hospitals and a number of projects implemented by non-governmental organizations committed to HIV/AIDS patients. There is strong support from international palliative care organizations for the development of palliative care

Palliative care research capacity:

There is one researcher: Gulara Afandiyeva.

Palliative care collaboration:

- Sumqayit Interregional Cancer Clinic and AIDS Center of Ministry of Health of Azerbaijan Republic have been implemented within the framework of the Ministry of Health in collaboration with the Global Fund project.
- Pioneers in palliative care include: Open Society Institute; the Global Fund; and NGO "Hippokrates".
- World Hospice and Palliative Care initiatives are promoted in collaboration with OSI.

Worldwide palliative care alliance level of development:

3A (Isolated palliative care provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

In 2009, the textbook "Methodological Guidelines on the Organization of Palliative Care in Azerbaijan" was prepared by the Working Group on Palliative Care and PhD expert Gulara Afandiyeva; the book was recommended to be used as a basic source for educating the civil sector about palliative care.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: No development.
- Nursing: No development.
- Social work: A number of pilot projects were initiated in Azerbaijan in 2010 by OSI: two projects at the State hospitals (Sumqayit Inter-regional Cancer Clinic and AIDS Center of Ministry of Health of Azerbaijan Republic) and six pilot projects implemented by NGOs (in Sumqayit and Baku cities and Lenkoran, and Hacıqabul regions). In the framework of the above mentioned projects, palliative care training for social workers was implemented. The main trainer was Gulara Afandiyeva who paid special attention to providing palliative care for injecting drug users at the end of life.
- Other professions: No development.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: The subject of palliative care was included as a part of the Family Medicine program in the Azerbaijan State Medical Institute.
- Nursing: No development.
- Social work: No development.
- Other professions: No development.

Translation of palliative care documents or other materials:

There is no information available at this time.

Initiatives to develop healthcare professional leadership in palliative care:

There is no information available at this time.

Officially recognized medical certification:

There is no officially recognized medical certification. There is however a process of accreditation as the subject of palliative care was included as a part of the Family Medicine program in the Azerbaijan State Medical Institute.

Capacity of palliative care workforce training in Universities and Medical Schools:

There is one medical university in Azerbaijan and palliative care is a mandatory component of medical curricula; there are also seven medical colleges (Source: National Survey).

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

There are no special developments, opportunities or barriers relating to the availability of essential medications.

Developments/opportunities/barriers relating to the accessibility of essential medications:

There are no special developments, opportunities or barriers relating to the accessibility of essential medications.

Developments/opportunities/barriers relating to the affordability of essential medications:

There are no special developments, opportunities or barriers relating to the affordability of essential medications.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

There is no information available at this time.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- A palliative care needs assessment for the republic of Azerbaijan was undertaken in May, 2007, supported by the International Palliative Care Initiative, Public Health Program, Open Society Institute; it was presented at the Round Table devoted to International Palliative Care Development involving multi-sectoral representatives and the Ministry of Health;
- Palliative care was included in the action plan of the Global Fund project (2006–2011);
- A Working Group was created within the Center of Public Health and the Ministry of Health;
- A Working Group developed a policy document and guidelines on palliative care; the documents were presented at the Round Table devoted to International Palliative Care Development involving multi-sectoral representatives and the Ministry of Health.

The impact of these policy changes and ways in which they have been important:

- Legislation changes resulted from these activities; palliative care was included in the "AIDS Law" and the "Law on Social Services" of Republic of Azerbaijan and Cabinet Ministers signed government orders on the next steps in the development of palliative care in the country.
- The provision of palliative care commenced at the State hospital for PLWHA in cooperation with the community of PLWHA.

Development of a national palliative care consensus:

The methodological coordinator of the Palliative Care Working Group (Gulara Afandiyeva) developed Guidelines on Palliative Care and discussed them with other Working Group members and international palliative care expert Stephen Connor before they were published. This textbook was accepted as the main source of learning material for the teaching of palliative care in Azerbaijan.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

There have been a number of significant meetings with stakeholders and policy makers to develop palliative care strategies; in 2008, 2010 and 2011 with multi-sectoral representatives and Members of Parliament.

Development of an advocacy framework for integrating palliative care into the health care system:

A strategy has been developed for integrating palliative care into the health care system but integration has not yet been achieved; the project is a pilot one as standards have not yet been fully approved as a part of the Azerbaijan national healthcare system.

Strategies to improve political awareness and government recognition of palliative care:

- There have been presentations on palliative care achievements since 2007 and a palliative care needs assessment has been undertaken;
- A film was produced with the active participation of cancer patients and PLWHA to demonstrate the need for palliative care. The film also demonstrated the willingness of key stakeholders and policy makers to establish and develop palliative care in Azerbaijan;
- Development of civil sector opportunities (policy document, guidelines, projects, etc.) and active cooperation with parliamentary committees.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

- OSI International Palliative Care Program (Director, Mary Callaway) has been financing the program to develop palliative care in Azerbaijan since 2001;
- Global Fund have provided funding since 2006 (two projects) up to the present day (eight projects in total).

Involvement with the European Union in relation to hospice and palliative care initiatives:

There is no information available at this time.

Development of initiatives framing palliative care as a 'human right':

Round Tables were devoted to the concept of palliative care as a human right; articles, interviews and films on palliative care as a fundamental human right have been produced.

General legislation relating to palliative care:

Palliative Care was included in the "AIDS Law" and "Law on Social Services" of Republic of Azerbaijan.

Published national documents relating to palliative care standards and norms:

"Methodological Guidelines on the Organization of Palliative Care in Azerbaijan" were published in November 2011.

National Plan or Strategy of Palliative Care:

There is no information available at this time.

National Cancer Control Strategy:

There is a National Cancer Control Strategy but it does not contain an explicit reference to palliative care provision.

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy but it does not contain an explicit reference to palliative care provision.

National Primary Health Care Strategy:

There is a National Primary Health Care Strategy but it does not contain an explicit reference to palliative care provision.

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

There is no information available at this time.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

Opioids are available in ICU units in inpatient facilities, and in pharmacy outpatient facilities. Opioids (injectable) may only be prescribed by a doctor (only an oncologist) in an outpatient facility and only for a maximum of two days. A general practitioner is not allowed by Law to prescribe opioids for patients. In inpatient facilities, opioids are prescribed in single dosage. There are no oral opioids available in Azerbaijan. There are no pain guidelines in Azerbaijan.

Funding of palliative care services:

- There is no payment for palliative care consultation.
- There is no payment for palliative care hospitalization.
- Full payment is required for palliative care medication.

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006**Change in public awareness or perception of hospice and palliative care:**

The project "Palliative care and Human rights" was implemented by the NGO "Hippokrates" in 2009 and financed by the OSI-Soros Foundation and International Federation for Health and Human Rights (IFHHRO); within this framework, a short film about palliative care was produced, translated and broadcast on Azerbaijan television.

Major public discussion, debate or controversy about hospice and palliative care:

There is no information available at this time.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

There is no information available at this time.

Hospice or palliative care 'success' stories:

There is no information available at this time.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is no information available at this time.

A palliative care needs assessment for Azerbaijan was undertaken in 2007, a National Palliative Care Task Force was established in 2008, and the concept of palliative care was included into the Law of Azerbaijan Republic on Social Services in 2010

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

- The Law of the Azerbaijan Republic "On population health protection" acknowledges the right for the "protection of physical and psychic health of every man" and aims at creating conditions for "provision of medical care" to the population of Azerbaijan. The law pays particular attention to the issues of protecting "the rights and freedoms of any man and citizen" of the Azerbaijan Republic and guaranteeing "rendering of medical and social aid for population groups" (Chapter 1, Article 3).
- To this date, absence of State Policy and a National Program has significantly hampered the development of palliative care in Azerbaijan: there has been a lack of institutional and human resources for establishing palliative care institutions and service networks, a methodological base, standards and medical protocols; there has also been a lack of training of medical and social workers in providing palliative care.
- Palliative care is not recognized as a medical specialty and appropriate inter-agency collaboration and interdisciplinary cooperation in the field of palliative care is lacking. In combination with insufficient funding, incorrect public health and social protection measures complicate the formation of effective palliative care provision.
- The problem of accessibility of essential medications for effective pain relief is still unsettled; the prescription of opioids for terminally-ill patients with chronic pain in the necessary form and quantity faces various obstacles (especially for non-cancer patients). There are strict regulations relating to the prescription of opioids for inpatients and for use at home. The limited access to effective pain relief and essential medicines, low accessibility to palliative care institutions and services, and the lack of adequately trained specialists restricts the provision of adequate palliative care.
- There is a necessity for the State to support, control and adequately fund palliative care and provide various levels of medical care to people with different types of diseases throughout the territory of Azerbaijan. One of the most important aspects of the future development of palliative care in the country is to draw the attention of the Government to the rendering of palliative care to terminally-ill patients.

The development of palliative care in Azerbaijan should be an inseparable part of national healthcare policy and be based on the following four main principles: availability; accessibility; acceptability; and quality.

- Availability of palliative care services implies availability of a sufficient number of facilities, taking into account the level of development and economic state of the country.
- Accessibility implies four parallel parameters: Non-discrimination - palliative care facilities and services must be accessible to everyone, particularly to the most vulnerable categories of population regardless of their race and ethnicity, gender and age, education, social status and location; Physical accessibility - palliative care facilities and services must be located in places where all members of the population can safely access them; Economic accessibility - every resident of the country must be able to afford palliative care services; Accessibility of information - accessibility includes the right of all people (patients, relatives and/or guardians) to request and receive correct and timely information about the diagnosis and expected plan of palliative care activities in accordance with all legal and ethical norms.
- Acceptability requires that palliative care services respect the cultural and ethical needs of patients, including whether they belong to a certain minority, people or community and in accordance with the requirements of gender and life cycle.
- Quality requires that palliative care functions properly from the point of view of science and medicine and corresponds to the highest standards of quality. The positive and negative lessons from the experience of other countries needs to be learnt; this information and new ideas from participants in the palliative care sphere would create the background for development of trans-national communications and new political strategies.

Most significant issues facing hospice and palliative care in the next three years:

- To overcome the problem of accessibility to effective pain relief and the prescription of opioid analgesics for use at home by patients with chronic pain.
- The system of public awareness about palliative care issues is also important. Low level of awareness results in the passive participation of non-governmental organizations in the implementation of palliative care.

Implications for palliative care relating to the current economic crisis:

- Improvement of the State Policy and National Program on Palliative Care;
- Development of the institutional and human resources for establishments and service networks, a methodological base, standards, medical protocols and training of medical and social workers in providing palliative care.

References

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In 2010, palliative care became a part of the pre- and post-diploma curricula of physicians, social workers and psychologists at Azerbaijan Medical University, Azerbaijan State Advanced Training Institute for Doctors and Baku State University

Belarus¹

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 7-16 (n/a) |
| Hospital palliative care support team | 0 |
| Home palliative care support team | 5 (n/a) |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 13 (224) |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 2 (58) |
| Day hospice/day care centre | 3 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

Dr. N. Antonenkova, Dr. O. Mychko (adult); Dr. N. Savva, Dr. A. Garchakova (children).

Additional comments:

There is no information available at this time.

Palliative care services for children:

There are seven paediatric volunteer hospice teams (three beds): there is one paediatric inpatient hospice (three beds) and one paediatric day hospice; there are seven paediatric home palliative care support teams.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

- 1994** PCO "Belarusian children's hospice" is established.
- 1998** The World Health Organization document "Cancer pain relief and palliative care in children" is translated into Russian and distributed to hospitals and oncologic dispensaries.
- 2000** Gomel children's hospice is established on the initiative of the Belarusian Children's Hospice.
- 2002** Vitebsk children's hospice is established on the initiative of the Belarusian Children's Hospice.
- 2003** Mogilev children's hospice is established on the initiative of the Belarusian Children's Hospice.
- 2004** Pinsk children's hospice is established on the initiative of the Belarusian Children's Hospice.
- 2004** PCO "Belarusian children's hospice" mark the publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organisation of palliative care) by including the document in palliative care lectures which take place at the hospice.
- 2005** Belarusian Children's Hospice (with Hilfswerk Austria/TACIS support) starts a new programme to create the first mobile palliative care service for adults in the Republic of Belarus.

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- 2006: The decree of Health Care Committee of Minsk City Executive Committee of the 14.03.2006 №147 "About the organization of the state institution palliative care hospital - Hospice";
- 2008: The act of the Ministry of Health of the Republic of Belarus of the 20.12.2008 №225 «About the issues of organization of palliative care service for patients with life-limiting oncologic disease, affirmation of the Instruction of organization of activity of the Hospice...» The decree of Ministry of Health of the Republic of Belarus of the 26.03.2008 №232 « About the affirmation of the primary medical documentary forms in a hospice...»;
- 2010: The decree of Ministry of Health of the Republic of Belarus of the 09.07.2010 №720 «About the affirmation of pattern board for medical and another staff of a hospice...» The decree of Ministry of Health of the Republic of Belarus of the 10.12.2010 №1318 « About the affirmation of the clinical protocol Pharmacotherapy of chronic pain at patients with oncologic pathology» The decree of Health care Committee of Minsk City Executive Committee of the №394 01.07.2010. «About palliative care service to adults of the city Minsk »;
- 2011: The decree of Health care Committee of Minsk City Executive Committee of the №533 12.08.2011. «About opening a palliative care department "Hospice" on the base of the hospital № 11 » The decree of Ministry of Health of the Republic of Belarus of the 10.11.2011 №1092 «About the organization of palliative care service to adults in the Republic of Belarus ».
- 2012: The organisation of palliative care is discussed at a high level in the Ministry of Health of the Republic of Belarus. On November 29th 2012, the concept of palliative care for adults in the Republic of Belarus was adopted.

Overall progress in hospice and palliative care:

Hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: a new inpatient hospice, day hospice and palliative care unit for adults have been opened.
- Nursing homes: There are more than 100 Nursing homes (2,485 beds) in Belarus.
- Residential homes for the elderly: There are a lot of residential homes for the elderly in Belarus.
- Other community settings: No development.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

- In 2011 indications for 'non-cancer' adult patients were approved. 'Non-cancer' adult patients receive a variety of palliative care services in Belarus.
- The needs of 'non-cancer' patients have been addressed in paediatric palliative care.

Perceived barriers to the development of hospice and palliative care:

(i) Palliative care is not included in the Public Health Code (ii) The lack of palliative care specialists (iii) A lack of availability of oral opioids (iv) A lack of information about palliative care (v) Insufficiently integrated medical and social services.

Perceived opportunities for the development of hospice and palliative care:

(i) The commitment of the government to include palliative care in the Public Health Code (ii) The presence of non-governmental organizations which have experience in palliative care (iii) The raising of awareness about palliative care amongst society.

Other issues relevant to the development of hospice and palliative care:

- The government supports palliative care for adults;
- The territory for building a new hospice for adults in Minsk was donated by the government in 2010.
- The territory for building a new hospice for children was donated by the government in 2011. The project will work in conjunction with "Belarusian Children's Hospice".

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

There is no information available at this time.

Directory or catalogue of palliative care services:

There is a catalogue of palliative care services in Belarus, according to the decree of Ministry of Health of the Republic of Belarus of the 10.11.2011 №1092.

Congresses, scientific meetings or scientific journals in palliative care:

- There are National and International Congresses on Palliative Care (adults and children): twice per year (adults) attended by approximately 60-70 healthcare professionals; and bi-annually (children) attended by approximately 150 healthcare professionals.
- There are more than 20 regional scientific meetings attended by approximately 800 healthcare professionals.

A new inpatient hospice, day hospice and palliative care unit for adults have been opened. Palliative care services for 'non-cancer' adult patients have been improved as have paediatric palliative care services

Palliative care research capacity:

There are palliative care researchers in Belarus: Dr. L. Zhilevich, Dr. O. Mychko (adult), Dr. N. Antonenkova, Ministry of Health of the Republic of Belarus, State Hospital of Palliative Care “Hospice”, N. N. Alexandrov National Cancer Center of Belarus; Dr. N. Savva, Dr. A. Garchakova (children), Belarusian Children’s Hospice, Belarusian Children’s Hospice.

Palliative care collaboration:

- There is collaboration in adult palliative care initiatives with the Red Cross (pilot projects) and in paediatric palliative care initiatives (home care and psycho-social care) with the Ministry of Health and seven regional hospices.
- There are a number of twinning initiatives: NGO Holland Group SRK (adults); Richmond House, London (children); Belarus is a member of the International Children’s Palliative Care Network; a partner with the Fund for Development of Children’s Palliative Care (Russia); a partner with the UK charity ‘Friends of Belarusian Children’s Hospice’, and the UK charity ‘Chernobyl Children’: healthcare professionals have received adult palliative care training in Holland, and paediatric palliative care training in a number of Former Soviet Union countries.
- Pioneers of palliative care in Belarus are Minsk Adult Hospice (governmental organisation since 1994) and Belarusian Children’s Hospice (charitable organisation since 2005).
- Belarusian Children’s Hospice celebrated World Hospice and Palliative Care Day in 2010.

Worldwide palliative care alliance level of development:

4A (Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

Palliative care training became available as a post-graduate course.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: palliative care is not a mandatory component in the general program of the Belarusian Medical Universities; from 2012, palliative care is available as an elective course.
- Nursing: Palliative care is included in the general program of the Belarusian Medical colleges-
- Social work: Palliative care training is available as a part of social projects
- Other professions: No development.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: Palliative care training became available as a post-graduate course.
- Nursing: Palliative care training became available as a post-graduate course.
- Social work: Palliative care training is available as a part of social projects.
- Other professions: No development.

Translation of palliative care documents or other materials:

The WHO guidelines, the ACT recommendations, and a number of other publications in the area of palliative care for children and adults have been translated.

Initiatives to develop healthcare professional leadership in palliative care:

The National Resource Centre of Children’s Palliative Care Act (2011); the Association of Children’s Palliative Care within Eastern Europe is to be created soon.

Officially recognized medical certification:

There is no information available at this time..

Capacity of palliative care workforce training in Universities and Medical Schools:

- Belarus has four medical Universities, an Academy of post-graduate education and six Medical colleges (source: Ministry of Health);
- There are no palliative care professors of any kind in Universities and Medical Schools.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- Morphine ampules and Tramadol are available; Duragesic and Hydromorphone lozenges are registered: oral morphine is not available and some other forms are not registered (for example, codeine);
- There is fear on the part of some physicians to prescribe opioids;
- There is a lack of awareness about opioids amongst some physicians.

Developments/opportunities/barriers relating to the accessibility of essential medications:

There is a difficulty with accessibility across rural locations but no accurate monitoring of this problem has been undertaken.

Developments/opportunities/barriers relating to the affordability of essential medications:

All essential medications are free of charge for patients in Belarus.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

- The Ministry of Health of the Republic of Belarus has approved regulations relating to opioid access (and controls the process).
- A range of training courses about opioids are provided for medical staff in hospitals.

Initiatives to promote attitudinal change in relation to ‘opiophobia’:

A range of training courses are held systematically to raise awareness of opioid prescribing.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

All essential medications are free of charge for patients in Belarus, so there are no problems in this area.

Initiatives that consider access to essential medication as a legal and human right:

All essential medications are free of charge for patients in Belarus, so there are no problems in this area.

The government has included palliative care in the Public Health Code. In 2012, the organisation of palliative care was discussed at the Ministry of Health and the concept of palliative care for adults was adopted

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- 2006: The decree of Health Care Committee of Minsk City Executive Committee of the 14.03.2006 №147 "About the organization of the state institution palliative care hospital - Hospice";
- 2008: The act of the Ministry of Health of the Republic of Belarus of the 20.12.2008 №225 «About the issues of organization of palliative care service for patients with life-limiting oncologic disease, affirmation of the Instruction of organization of activity of the Hospice...» The decree of Ministry of Health of the Republic of Belarus of the 26.03.2008 №232 « About the affirmation of the primary medical documentary forms in a hospice...»;
- 2010: The decree of Ministry of Health of the Republic of Belarus of the 09.07.2010 №720 «About the affirmation of pattern board for medical and another staff of a hospice...» The decree of Ministry of Health of the Republic of Belarus of the 10.12.2010 №1318 « About the affirmation of the clinical protocol Pharmacotherapy of chronic pain at patients with oncologic pathology» The decree of Health care Committee of Minsk City Executive Committee of the №394 01.07.2010. «About palliative care service to adults of the city Minsk »;
- 2011: The decree of Health care Committee of Minsk City Executive Committee of the №533 12.08.2011. «About opening a palliative care department "Hospice" on the base of the hospital № 11 » The decree of Ministry of Health of the Republic of Belarus of the 10.11.2011 №1092 «About the organization of palliative care service to adults in the Republic of Belarus ».

The impact of these policy changes and ways in which they have been important:

In relation to palliative care for adults, a number of inpatient departments have been opened, but the quality is at the same level; although there are a lot of palliative care centres, their number does not depend on local demand. The quality of paediatric palliative care has increased substantially, and a multiplicity of services can now be observed.

Development of a national palliative care consensus:

A draft of a national palliative care consensus has been developed. There is currently a public discussion of the draft.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

Meetings at the Ministry of Health of the Republic of Belarus; the Republic Palliative Care Meeting; the International Conference "Children's Palliative Care in Eastern Europe".

Development of an advocacy framework for integrating palliative care into the health care system:

Two videos have been developed and more than 40 journal articles have been published.

Strategies to improve political awareness and government recognition of palliative care:

A number of meetings and teleconferences have been held, and policy makers have been invited to a number of palliative care events.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

- 12% of palliative care for adults is funded by private and voluntary organizations.
- Five lung ventilators were purchased by the Belarusian Children's Hospice, an inpatient department was opened by Gomel hospital funded by Belarusian Adult Hospice and the Belarusian government donated the territory for building a new paediatric hospice.

Involvement with the European Union in relation to hospice and palliative care initiatives:

- Palliative care physicians have participated in European and World Congresses and conferences; Global meeting in Vienna BHGI Fred Hutchinson Cancer Researcher Centre.
- The Belarusian Children's Hospice held their first international conference in October 2011, with representatives from WHO, ACT, and Chernobyl Children's Project; the first Deputy Minister of the Public Health Service also attended.

Development of initiatives framing palliative care as a 'human right':

There is no information available at this time.

General legislation relating to palliative care:

Palliative care amendments to the Public Health Code.

Published national documents relating to palliative care standards and norms:

Regulation documents from Ministry of Health, Belarus; organisation of palliative care for adults in Belarus - no. 48 (2001), no. 1430 (2005), no. 147 (2006), no. 225 and 1010 (2008), no. 720 (2010), no. 533 (2011), no. 1092 (2011). Also Symptom Control in Children/Adults (2011). Online standards are available at www.minzdrav.gov.by

National Plan or Strategy of Palliative Care:

There is a National Plan of Palliative Care in process and it is estimated that it will be completed by 2012.

National Cancer Control Strategy:

There is a National Cancer Control Strategy: the Government Program of Oncology (2010-2014) (includes provision of a mobile palliative care service).

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy: the WHO/Government Aids Program (does not contain palliative care provision).

National Primary Health Care Strategy:

There is a National Primary Health Care Strategy in Belarus.

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

The Department of Health has specific responsibility for the delivery of palliative care services: approving regulatory documents; supervision/provision of palliative care services; ensuring levels of quality in government hospitals, hospices, polyclinics, and all organisations with a medical licence for providing care and treatment.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

Monitoring the standard of palliative care is discussed at conferences.

Opioid legislation/Pain guidelines:

National Chronic Cancer Pain Pharmacotherapy Protocol for Adults, 2nd edition, 10/12/2010. There are also pain guidelines in process: National Non-Cancer Pain Pharmacotherapy Protocol for Adults (2012), National Symptom Control Protocol for Children (2012).

Funding of palliative care services:

- Government funding of palliative care services for adults in Belarus.
- No payment is required for palliative care consultation, hospitalization, or medication.

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

There have been some changes in public awareness and perception of hospice and palliative care due to coverage in the mass media.

Major public discussion, debate or controversy about hospice and palliative care:

There has been public discussion about hospice and palliative care on television; the main themes have been oncology, quality of life and “telling the truth”.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

A number of articles to broaden awareness and understanding of hospice and palliative care have been published in newspapers and posted on the internet.

Hospice or palliative care ‘success’ stories:

None to date, but this will be a goal for the future.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There are a lot of debates about this topic on television, but assisted dying is still officially forbidden in Belarus.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

- Palliative care for adults will develop both short-term and long-term assistance.
- To develop palliative care services (inpatient, day and home care) and integrate them into the national healthcare system.
- The main aim is symptom management (quality pain relief) and integration between social care agencies and public associations.
- With regard to children's palliative care there are some optimistic prospects. The project of building a new hospice for children will form a strong partnership between the government and the State medical setting. This partnership will result in an increase in the quality and extension of palliative care.
- There is a trend to increase the number of palliative care units for adults, but there is no variety in the forms of service provided. There is an absence of out-patient departments and a domiciliary service in adult palliative care and there are still problems relating to a lack of opioids. The process of developing standards and frameworks for the provision of palliative care should take place soon.

There has been much palliative care legislation passed by the Belarusian government. There has been increased awareness and recognition about palliative care amongst non-governmental organizations and also within Belarusian society

Most significant issues facing hospice and palliative care in the next three years:

- The establishment of a National Palliative Care Centre in Belarus.
- Integration of palliative care in the public health system.
- To implement the concept of palliative care in Belarus.
- Approval and introduction of the National Palliative Care Standard (Symptom Protocol).
- The new children's hospice is to have eight wards and will function as a centre for palliative care in Belarus. The role of the Belarusian Children's Hospice is to assist the government in conforming to European standards, to provide relevant information, to help purchase necessary equipment, and to launch new palliative care projects.

Implications for palliative care relating to the current economic crisis:

The most serious problem facing the development of palliative care in Belarus is not the current economic crisis, but rather a lack of experience. It is unreasonable to build so many inpatient departments and more necessary to focus on developing a variety of palliative care services and to consider the ways in which they can become integrated into the system of all medical structures.

References

Costello J, Gorchakova A. 2004. “Palliative care for children in the Republic of Belarus”. *Int J Palliat Nurs*; 10(4):197-200.”

Dangel T. 1999. “Belarussian viewpoint. The Belarus Children's Hospice”. *Eur J Palliat Care*; 6(1):28-30.”

Becker R. July 2006. “The legacy of Chernobyl: palliative services making a difference in Belarus”. *Int J Palliat Nurs*; 12(7):318-9.

Belgium¹

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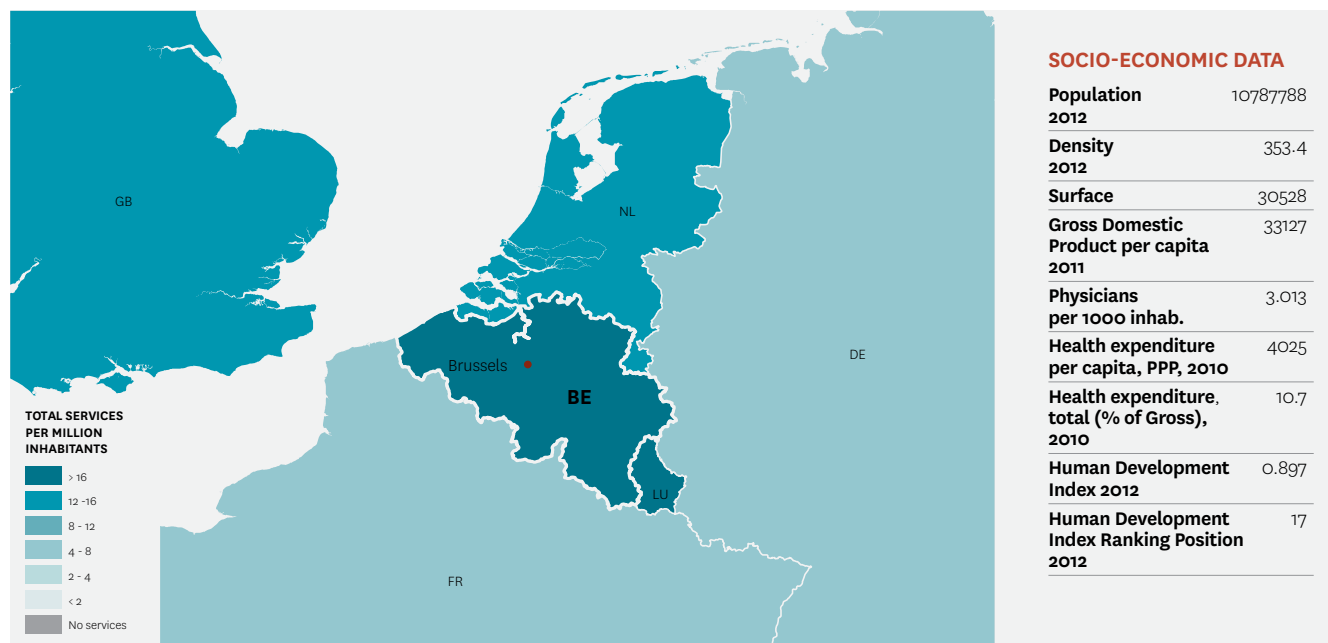
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 116 |
| Home palliative care support team | 28 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 49 (367) |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 2 (12) |
| Day hospice/day care centre | 10 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Evaluation report on palliative care from the Federal Evaluation Commission Palliative Care, May 2008. Available at: http://mailsystem.palliatief.be/accounts/15/attachments/rapporten/fed_evaluatieccl_mai_2008_rapport_2008_nl.pdf
- Fédération Wallonne des Soins Palliatifs. La revue des soins palliatifs en Wallonie, September 2008. Homepage at: <http://www.SoinsPalliatifs.be>
- Project palliative care, National institute for health and disability insurance (NIHDI), July 2004. Available at: <http://www.riziv.fgov.be/care/nl/palliativecare/pdf/report20040831.pdf>
- Flemish federation of palliative care. Available at: www.palliatief.be
- Brussels palliative care federation. Available at: <http://www.hospitals.be/fbbsp/> and <http://www.palliabru.be/>
- Data on inpatient hospices provided by physicians in both hospices; Bea Temmerman and Gert Biesmans
- www.palliatief.be

Additional comments:

- Volunteer Hospice teams do not exist in Belgium.
- According to legal regulations every hospital (except psychiatric, geriatric or re-validation services) must have a hospital palliative care support team.
- Brussels capital region has three home palliative care support teams, Flanders 15, the Walloon Region nine and the German Speaking Community one.
- In Belgium there are 51 Palliative Care Units (PCU) (379 beds). Two of the 51 are free standing units and fulfil the criteria of an inpatient hospice (49 PCU and two inpatient hospices).
- Flanders has seven palliative day care centres, the Walloon Region one and Brussels Capital Region has two.

Palliative care services for children:

There are seven paediatric mixed palliative care support teams that are based in seven hospitals in Belgium (three French speaking and four Flemish speaking) that also provide home care – they are hospital-based paediatric home palliative care teams.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

- 1987** The first palliative home care team is established.
- 1991** The first palliative care unit is established (in Brussels hospital).
- 1991** The first palliative care support teams form in hospitals.
- 1995** Regional "Networks for Palliative Care" are installed (by Law).
- 1998** The first palliative day care centre is opened.
- 2001** A palliative care support team is active in 72% of hospitals.
- 2001** A specialised nurse or support team is active in 50% of nursing homes.
- 2002** Five palliative day care centres become active (involving a specialised nurse, physician, psychologist or social worker) on an experimental basis.
- 2002** The Law on euthanasia is established.
- 2002** The Law on palliative care is established.
- 2002** The notion of 'palliative sedation' is developed (key person: Prof. Dr. Bert Broeckaert, Katholieke Universiteit Leuven).
- 2004** The Federation Palliative Care Flanders marks the publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organization of palliative care) by using the publication to argue for more governmental support for the further development and financial support of palliative care (oral presentation by the Chairperson of the Federation Palliative Care Flanders during the Conference for Palliative Care, organized by the National Health Insurance Organization on November 24th 2004).

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- Since 2006 a lot of work has been done (and continues to be done) on advance care planning (ACP): among other things a media campaign has been set up, brochures for the general population ("Also the last journey is something you want to discuss together") and for health care workers ("Giving the end of life back to the people") have been developed, and an informative website (www.delaatsteis.be) has been constructed. This focus on ACP stimulates further the work done to advance palliative care in the disease trajectory in order to avoid the reduction of palliative care to terminal care. Another project that is initiated in Flanders (the Dutch speaking part of our country) during the last years (and still continues) is the construction of guidelines for palliative care (cf. www.palliatie.be). Currently eight guidelines are published: Fatigue in the palliative phase of cancer; Hypercalcaemia; Hiccups; Shortness of breath; Coughing; Fever; Nausea and vomiting; Sedation (authors: Bert Broeckaert [KU Leuven] in collaboration with M. Desmet, A. Mullie, D. Declerck, J. Gielen, P. Vanden Bergh and Steering committee Ethics of the Federation Palliative Care Flanders).

Currently the revised version of this guideline is published (June 2012; same authors).

To ease the use of the guideline the same authors summarized the essence in a folder for physicians that will soon be made public. In addition, a leaflet was developed for the broader population (this can be downloaded from www.palliatief.be, 'Vers van de pers', 'Folder voor de brede bevolking over PALLIATIEVE SEDATIE');

- As executors of the law concerning palliative care (2002) a federal evaluation commission of palliative care was set up. This commission is composed of (among others) representatives of the three Federations of Palliative care in Belgium. It evaluates needs in relation to palliative care at regular intervals and the quality of the actions taken to meet these needs. The most recent report of this commission dates from 2008. Currently the commission focuses on the definition of palliative care and how this can be operationalized. More concretely, this operationalization examines frailty parameters, based on which three levels of palliative care needs and patients are differentiated. Inspiration for this work is the work done by Scott Murray and colleagues on the description of indicators for palliative care, as evidenced by among others the SPICT (cf. <http://www.palliativecareguidelines.scot.nhs.uk/careplanning/spict.asp>).
- In 2007, an adjustment of the financing of palliative care in hospitals was published. The further development of palliative care units and teams in hospitals was an important change to the provision of care in hospitals. Palliative patients in residential and nursing homes are not required to pay the fees of their GPs (under certain circumstances). The National Cancer Plan (March 2008) states that the expansion of palliative care should be actively supported. Palliative care services in residential and nursing homes, home care, palliative care in the hospital and palliative day care need to be further extended. A budget was foreseen for inter-university liaison teams for paediatric palliative care.
- Palliative care increasingly finds acceptance as a relevant research domain in the universities; different Flemish universities are currently undertaking research in the domain of palliative care. Important domains of expertise (which are elaborated in close collaboration with (or commissioned by) stakeholders, Flemish Agency of Care and Health, and experienced palliative care workers are the construction and testing of Flemish quality indicators for palliative care and the construction and implementation of a pathway of palliative care in primary care. This close collaboration between the clinic and research is an important achievement that needs to be further consolidated.
- With regard to education, steps are being taken to further the professionalization of and capacity building in palliative care. Examples are the development of a postgraduate course of palliative care for physicians, postgraduate courses of palliative care for nurses, and the development of competence profiles for nurses in palliative care.
- In 2009, the Belgian Health Care Knowledge Centre studied, in close collaboration with the three federations of palliative care and university teams, the situation of palliative patients in Belgium. The report 'The organisation of palliative care in Belgium' can be downloaded on <https://kce.fgov.be/nl/publication/report/organisatie-van-palliatieve-zorg-in-belgi%C3%AB> (in English).

Overall progress in hospice and palliative care:

Hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: Every hospital (except psychiatric, geriatric or revalidation services) must have a palliative support team (PST) with 24/7 on-call duty. In 2007 there was an increase in the funding of hospital support teams (19/06/2007).
- Nursing homes: Fees for GPs were fully reimbursed by health care for palliative patients in residential and nursing homes without a palliative statute under certain preconditions (16/02/2009); reimbursement for palliative care in nursing homes was established (8/10/2009); palliative care nurses were introduced into nursing homes (1/07/2008).
- Residential homes for the elderly: As for nursing homes.
- Other community settings: Reimbursement of physiotherapy for palliative care patients at home was established (1/07/2006 and 7/06/2007); experimental funding of day care centres commenced (8/12/2006). In 2009, a Law was passed relating to the recognition and financing of palliative home care teams for children (5/03/2009).

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

The focus on needs of 'non-cancer patients' has intensified since 2006. More concretely, some of the workgroups of the Federation of Palliative Care focus specifically on this topic, as illustrated by among others the work groups "Palliative Care for the Elderly" and "Palliative Care for Psychiatric Patients". Moreover, the broadening of palliative care to include non-cancer patients is one of the topics addressed in the workgroup Palliative Support Teams. The Pathway of Palliative Care in the Primary Care Setting explicitly aims at ameliorating palliative care for all patients in the primary setting. Lastly, the work done by the three Federations on the definition of palliative care patients explicitly uses frailty parameters that go beyond cancer patients.

Perceived barriers to the development of hospice and palliative care:

- Financial strain in all settings. Cuts (or status quo) in finances threaten palliative care workforce capacity in different care settings, during times where the care needs of a growing population of elderly people puts pressure on health care services;
- The fact that Belgium is a unique federal state with segregated political power across three levels (the federal government, the three language communities and the three regions) poses the risk that some decisions about funding or legislation are situated on different political levels - and political levels may shift responsibility to one another in times of elections;
- The global shortage of formal caregivers, especially in nursing and residential homes.

Perceived opportunities for the development of hospice and palliative care:

- The intensified collaboration between research and practice/stakeholders;
- The aging population. This growth implies a heavy pressure on manpower and financial means, but also implies an opportunity as it pressures politicians and society to consider topics such as advance care planning and palliative care;
- The vision statement of the Federation Palliative Care "On palliative care and euthanasia" about the relationship between euthanasia and palliative care opens a debate about non-ideological best practice in the interest of the patient.

Other issues relevant to the development of hospice and palliative care:

A vision text "On palliative care and euthanasia", in which it is explained that the Federation of Palliative Care Flanders does not consider palliative care and euthanasia as mutually exclusive concepts (the Dutch version can be downloaded on www.palliatief.be, 'Recente publicaties', 'Over palliatieve zorg en euthanasie').

Congresses, scientific meetings or scientific journals in palliative care:

- Flanders has an annual scientific palliative care meeting: the Flemish Congress on Palliative Care (9th Congress, Fall, 2012). The Flemish congress has approximately 800 participants (physicians, nurses, social workers, chaplains, psychologists, volunteers);
- Annually there is a joint research forum from the Netherlands and Flanders on palliative care;
- There is a palliative care journal: Nederlands-Vlaams Tijdschrift voor Palliatieve Zorg (Dutch-Flemish Journal of palliative care) that is published three times per year (<http://www.boomlemma.nl/gezondheidszorg/catalogus/nederlands-vlaams-tijdschrift-voor-palliatieve-zorg#>).

Palliative care research capacity:

- There is no structured national research programme but a number of universities have developed their own research programmes. The End-of-Life Care Research Group is part of the Faculty of Medicine and Pharmacy of the Free University of Brussels (VUB) and works with the Universities of Ghent and Antwerp. In Leuven, the School for Public Health Science and Centre for Hospital and Nursing Sciences at the Catholic University conducts research into different aspects of palliative care and the Centre of Biomedical Ethics and Law undertakes many research projects into advanced care planning, palliative care, euthanasia and other issues. The University of Antwerp has several palliative care research projects. In the Walloon region the different university centres for general medicine (Centre Universitaire de Médecine Générale - CUMG) undertake some research in palliative and end of life care. <http://www.endoflifecare.be/home>.
- Researchers: Johan Menten, Bert Brouckaert, Bernadette Dierckx de Casterlé, Bert Aertgeerts, Jan Delepeleire (Leuven); Peter Pype and Peter Demeulen-aere (Antwerp).

Palliative care collaboration:

- European research projects: Europall - IMPACT- PRISMA.
- Pioneers include: Prof Christian Deckers, Chantal Couvreur, Lisette Cuestermans, Dr. Josepha Debuysschere (Sister Leontine). In Belgium, the Briton Joan Jordan who had witnessed the fatal illness of her Belgian husband founded an organisation called 'Continuing Care' to promote palliative care in 1981. In 1985 the first palliative care service became operational when 'Continuing Care' started a specialised home care service in Brussels (Chantal Couvreur) and in the Cliniques Universitaires St Luc. Four beds in the cancer ward were allocated by Professor Christian Deckers for the treatment of patients with terminal cancer, leading to the building of an eight-bed palliative care unit (Unité de Soins Continues). Many individual and voluntary initiatives and projects of home care teams, hospital-based teams and palliative care units were established until 1991 when government funding (the so-called Busquin Experiments from 1991 to 1998) commenced. The programme included pivotal hospital-based mobile palliative care teams and thus was an incentive for sustained development of palliative home care teams, palliative support teams in hospitals and a geographical spread of residential palliative care units. In 1992, Professor Decker organised the second EAPC congress in Belgium (http://www.provant.be/binaries/TOK%20NieuwWelzijn-PalliatieveN-vWEB_tg_tcm7-99678.pdf; "History of palliative care in Europe" in Birgit Jaspers, Karen Van Beek, Johan Menten; "Assessing Organisations to Improve Palliative Care in Europe" (2010) SH Ahmedzai, X Gomez-Batiste, Y Engels, J Haselaar, B Jaspers, W Leppert, J Menten, JM Mollard, K Vissers (Editors).

Worldwide palliative care alliance level of development:

4B (Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision).

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

Belgium has three regional associations of palliative care as opposed to one national association (a Flemish, a Walloon and a federation from Brussels Capital Region); Walloon federation of palliative care (formed 1995) (<http://www.palliabru.be/Walloonregion:www.soinspalliatifs.be>); Flemish federation of palliative care (formed 1990); Pluralist federation from Brussels of palliative and continuing care (formed 1997) (www.palliatief.be Brussels).

Directory or catalogue of palliative care services:

Vademecum (2012) Palliative care in Belgium (edited by the Brussels palliative care federation). There is an online directory: <http://www.palliabru.be/neeerlanda-is/entreentl.htm>

Adjustment to the financing of palliative care in hospitals was published; the development of palliative care units in hospitals was an important element. The professionalization of, and capacity building in palliative care has been furthered

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

Training and education are developing with regard to palliative care both in the under-graduate and post-graduate system; a competence profile for nurses in palliative care is currently in development. In addition, work is done to develop training and education based on guidelines already developed regarding symptom management (see www.pallialine.be), as these reflect the most recent and evidence-based knowledge on the management of symptoms. Some research is planned and has been initiated with regard to effective training modes and the quality of current training in palliative care (by Dr. Peter Pype, UGent).

Specific developments in under-graduate palliative care education initiatives:

- Medicine: An important development is that the principles of pain and symptom management at the end-of-life are being taught in the basic education of physicians in most Flemish universities;
- Nursing: An important development is that the principles of pain and symptom management at the end-of-life are being taught in the basic education of nurses in most Flemish colleges;
- Social work: No major developments;
- Other professions: No major developments.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: Since the academic year 2010-2011, a collaboration of three Flemish universities has organized a one-year postgraduate course for physicians, facilitated by the Federation of Palliative Care Flanders.
- Nursing: Recently (for one or two academic years) postgraduate courses in palliative care have been organised by the colleges of nursing and midwifery in Flanders (in close collaboration with the Palliative Care Networks).
- Social work: Specialized (mostly short) training courses are organised by Federation Palliative Care Flanders, the networks, and other training organizations.
- Other professions: Specialized (mostly short) training courses are organised by Federation Palliative Care Flanders, the networks, and other training organizations.

Translation of palliative care documents or other materials:

The Supportive and Palliative Care Indicator Tool was translated into Dutch (and also recently into French).

Initiatives to develop healthcare professional leadership in palliative care:

There is no information available at this time.

Officially recognized medical certification:

There is no official certification but there are "other awards" in Belgium. In Flanders, the Flemish universities and the Flemish Federation of Palliative Care provided basic post-graduate training in palliative care for physicians (GPs and specialists) until 2008-2009. In 2010-2011, the Flemish universities and the Flemish Federation of Palliative Care commenced an advanced palliative care education course for physicians (three workshops of 20 hrs duration). The French speaking Universities used to organise a postgraduate course in palliative care training of one-year minimum which consisted of theoretical lessons (minimum 80 hrs), bedside teaching of 140 hrs and an internship (the course ceased in 2008). In 2011, the Catholic university of Louvain (UCL) in Brussels commenced an inter-university course (with the University of Lille in France) about palliative care and quality of life for physicians and other paramedics (<http://www.uclouvain.be/index.html>) – "Le projet RAMPE (Réseau d'Aide en médecine Palliative Extra-muros)", financed by pharmaceutical companies. In 1998 a "sensitization campaign" relating to palliative care commenced for general practitioners (of 30 hrs duration).

Capacity of palliative care workforce training in Universities and Medical Schools:

- There are seven medical schools in Belgium: four Flemish speaking universities and three French speaking universities - all provide "some" mandatory palliative care teaching.
- It is estimated that there are six assistant professors and six "other category" of professors working in Universities and Medical Schools in Belgium.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

Since January 2006, there have been no important or relevant developments with regard to the availability of essential medications.

Developments/opportunities/barriers relating to the accessibility of essential medications:

Since January 2006, there have been no important or relevant developments with regard to the accessibility and affordability of essential medications.

Developments/opportunities/barriers relating to the affordability of essential medications:

Since January 2006, there have been no important or relevant developments with regard to the affordability of essential medications (although some of the newer medications are expensive).

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

This topic is addressed within a number of training courses where "myths" about the effects of opioids are discussed.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

No such initiatives are required as Belgium has a strong social security system; this topic is not one of our priorities.

Initiatives that consider access to essential medication as a legal and human right:

There are no special initiatives in this area.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- The most important laws concerning palliative care were published in 2002, by the law concerning palliative care (14/06/2002), euthanasia (28/05/2002), and patient rights (22/08/2002); since then the debate has been lively. Currently, there is much political debate relating to whether or not (and how) euthanasia should or can be expanded to patients with dementia and minors;
- Since 2006, some Royal Decrees concerning palliative care were published, by: Reimbursement of physiotherapy for palliative care patients at home (1/07/2006 and 7/06/2007); Experimental funding of day care centres (8/12/2006); Adjustment (increase) in funding of hospital support teams (19/06/2007); Fees for GP fully reimbursed by health care for palliative patients in residential and nursing homes without a palliative statute under certain preconditions (16/02/2009); Registration of euthanasia (27/04/2007); Exemption of personal fees in nursing homes (16/06/2009); Reimbursement in nursing homes (8/10/2009).
- In 2008 (30/05/2008), the Flemish Government regulated volunteer work. A volunteer organization involved in palliative care and consisting of at least 20 volunteers is entitled to financing from the Flemish government.
- In 2009, a law was published about the recognition and financing of palliative home care teams for children (5/03/2009). The National Cancer Plan (Federal Government; March 2008) has furthered the active support of palliative care.

The impact of these policy changes and ways in which they have been important:

All these laws and royal decrees have facilitated the further development of palliative care in different settings, such as nursing homes, and for different populations, such as children. Yet due to the unique organisation of Belgium (and the lengthy residency of the government), further initiatives (for example, relating to financing and professional titles) have been delayed.

Development of a national palliative care consensus:

- There has been development of guidelines with regard to symptom management in palliative care (cf. www.palliative.be);
- A pathway of palliative care in primary care has been developed by a research group of the University of Antwerp, in close collaboration with stakeholders and palliative care workers, commissioned by the Flemish Agency of Care and Health and the Federation of Palliative Care Flanders. This pathway has been pilot tested and there are plans to implement the pathway in collaboration with the National Institute for Health and Disability Insurance;
- As execution of the law concerning palliative care (2002) a federal evaluation commission of palliative care was set up. As already mentioned, this commission is composed of (among others) representatives of the three Federations of Palliative care in Belgium and it has the purpose to evaluate at regular intervals the needs with regard to palliative care and the quality of the actions taken to meet those needs. The most recent report of this commission dates from 2008; Vision statement on palliative care and euthanasia of the Federation of Palliative Care Flanders.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

Although national meetings on palliative care are unfortunately still lacking (due to the federal and regional organisation of the country), there is a clear movement in the palliative care landscape in Flanders to include stakeholders, policy makers and experienced palliative care workers in discussions of research results and in the execution of research projects, and vice versa. There has been close collaboration between research, clinic and stakeholders during the construction of the Pathway of Palliative Care in Primary Care, during the construction of Quality Indicators of Palliative Care in Flanders (see also www.fliece.be), during the campaign concerning advance care planning (www.delaatstereis.be) and during the progress of the FLIECE research (Flanders Study to Improve End-of-Life Care and Evaluation Tools research - a four-year inter-university research and valorisation project, cf. www.fliece.be).

Development of an advocacy framework for integrating palliative care into the health care system:

The most important framework is the Evaluation Commission for Palliative Care, which was initiated in response to the publication of the law on Palliative Care.

Strategies to improve political awareness and government recognition of palliative care:

The following strategies have been undertaken: A monthly newsletter of the Federation of Palliative Care Flanders which describes developments within palliative care practice as well as within (inter)national research on palliative care (see www.palliatief.be > Publicaties > Tijdschrift en Nieuwsflash); the more active use of press releases by the Federation of Palliative Care Flanders on topics which are set as priorities in the development of palliative care; for example, finances in palliative care etc. Related to this more active approach is also the collaboration with production houses for the making of some DVDs, for example on palliative sedation.

A federal commission of palliative care was established which evaluates needs in relation to palliative care at regular intervals and the quality of the actions taken to meet these needs. A palliative care leaflet was developed for the broader population

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

The Royal Decrees and regulations previously mentioned ensure that palliative care is mainly publicly funded. Depending on the setting the palliative care service will receive funding from the federal government and/or from the respective communities. Sometimes this public funding is completed with private funding. As already indicated, some Royal Decrees have regulated the financing of services or the fees patients have (or have not) to pay since 2006: Reimbursement of physiotherapy for palliative care patients at home (1/07/2006 and 7/06/2007); Experimental funding of day care centres (8/12/2006); Adjustment (increase) in funding of hospital support teams (19/06/2007); Fees for GP fully reimbursed by health care for palliative patients in residential and nursing homes without a palliative statute under certain preconditions (16/02/2009); Exemption of personal fee in nursing homes (16/06/2009); Reimbursement in nursing homes (8/10/2009); In 2008 (30/05/2008) the Flemish Government regulated volunteer work. A volunteer organization involved in palliative care and existing of at least 20 volunteers is entitled to financing from the Flemish government; In 2009 a law was published about the recognition and financing of palliative home care teams for children (5/03/2009).

Involvement with the European Union in relation to hospice and palliative care initiatives:

The Dutch speaking part of Belgium was represented in the European research project PRISMA. Flemish universities and the Federation of Palliative Care Flanders took part in the elaboration of different work packages of this project. Also the final conference of PRISMA was held in Brussels; the director of the Federation of Palliative Care Flanders, Paul Vanden Berghe PhD, is member of the EAPC board.

Development of initiatives framing palliative care as a 'human right':

Palliative care as a human right was inscribed in the law on palliative care of 2002. Yet the further communication of this basic principle is everyday work of palliative care workers and the Federations and forms the basis of all communication towards the general public and stakeholders.

General legislation relating to palliative care:

28-05-2002 concerning euthanasia: the physician always needs to discuss the option of palliative care with the patient. 14-06-2002 1. Every patient has the right to receive information about his health and the possibilities to receive palliative care. Except in emergencies, the patient needs to give his permission to perform investigations and to receive treatment 2. Every patient has the right to receive palliative care. 3. There needs to be an improvement in palliative care services 4. An evaluation commission (consisting of representatives of the three palliative federations, several health insurance funds and external experts) has been implemented and will make an evaluation that will be presented to the government every two years. 22-08-2002 law about patient's rights.

Published national documents relating to palliative care standards and norms:

Yes (printed). Thanks to the numerous regulations palliative care is well structured.

National Plan or Strategy of Palliative Care:

- There is no specific National Plan of Palliative Care, but the law on palliative care and numerous Royal Decrees and regional regulations means that palliative care is very well organised. According to the palliative care law a commission has to make an evaluation about palliative care development every two years and has to present this to the federal government. All the different palliative care settings have the task of making palliative care available and accessible in the home setting, nursing homes, hospitals and PCUs in their covering region. Palliative care services need to keep records of every patient they provide care for, the activities (medical, medical-technical and nursing activities) need to be recorded/registered and they have to make annual activity and evaluation reports.
- Belgium is divided into 25 well-organised Palliative Care Networks. These Palliative Care Networks include geographically well-defined areas covering 200,000-1,000,000 inhabitants, including hospitalised patients and patients in residential and nursing homes in that region. The networks liaise with the hospital support teams, the PCUs and the residential and nursing homes in their region and stimulate collaboration and communication between these different intramural and extramural settings. They have regular meetings with the coordinating federation to report shortcomings and pitfalls.

National Cancer Control Strategy:

The National Cancer Plan 2008-2010 (March, 2008) initiative states that the expansion of palliative care shall be actively supported. Palliative care services in residential and nursing homes, home care, palliative care in the hospital and palliative day care need to be further extended and a budget is foreseen for 2009 and 2010 for an inter-university liaison team for paediatric palliative care.

National HIV/AIDS Strategy:

There is no National HIV/AIDS Strategy.

National Primary Health Care Strategy:

Since 1990 there have been Flemish decrees relating to primary health care that resulted in a collaborating initiative for primary health care (SELS or Samenwerkingsinitiatief in de EersteLijnsgezondheidszorg - <http://www.vlaamse-sels.be/>) in 2004. There is no explicit reference to palliative care provision (but this has already been determined within Legislation and Royal Decrees).

Designated policy maker for the delivery of palliative care services:

According to the palliative care law of 2002: An evaluation commission (consisting of representatives of the three palliative federations, several health insurance funds and external experts) will make an evaluation that will be presented to the government every two years. They give advice to the policy makers to optimize the delivery of palliative care services.

Department of Health specific responsibility for the delivery of palliative care services:

The Flemish federation evaluates palliative care teams and their quality of provision; the federal government will fund these services following approval by the Flemish federation.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

The activities of different palliative care services (medical, medical-technical and nursing activities) need to be recorded and annual reports have to be made (as per Royal Decrees). The regional governments will visit the different palliative care services every two years to evaluate them and report back to the federal government; when they receive a positive evaluation they get funding from the government.

Opioid legislation/Pain guidelines:

- A prescription has to be fully written by a physician and there are no opioid limitations; any pharmacy can provide them.
- Pain guidelines are available in printed form: a practical manual of pain and symptom control in palliative care is available from the Palliative Care Hospital support Team of the UZ Leuven. A Second revised edition from 2009 is available online, edited by ACCO Leuven. UZ Gent and a number of other hospitals have their pain guidelines available online (see www.pallialine.be - guidelines for palliative care from the Flemish federation of palliative care). Further guidelines on pain are in progress.

Funding of palliative care services:

- There is no payment required for palliative care consultation or hospitalization;
- A partial payment is required for medications.

The National Cancer Plan (2008) supports the expansion of palliative care. Postgraduate courses of palliative care for nurses and physicians have been developed at some universities and research in palliative care actively promoted

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

There is more openness to discuss topics such as euthanasia and palliative care and the ways in which they potentially relate to each other.

Major public discussion, debate or controversy about hospice and palliative care:

- The media campaign concerning advanced care planning "Also the last journey is something you want to discuss together ..." involved distributing flyers, brochures and posters, and delivering lectures and training;
- There was a press release and symposium relating to "On palliative care and euthanasia"; a symposium was held during which a DVD was shown and a debate was held (the national press covered this event).

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

A number of different articles and press releases have been used to raise awareness about hospice and palliative care.

Hospice or palliative care 'success' stories:

There are many hospice or palliative care 'success' stories; however, workers, patients and caregivers keep us informed about ways to improve palliative care services.

Initiatives seeking the legalisation of euthanasia or assisted dying:

Reference: laws of 2002.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

We hope to continue the development of palliative care. More concretely, we hope to continue to further the current initiatives towards deepening and broadening palliative care knowledge and research. Capacity building will be a main aim of our future work.

Most significant issues facing hospice and palliative care in the next three years:

- Capacity building and safeguarding of manpower within palliative care workforce capacity;
- The further strengthening of the knowledge base for spiritual and existential care.

Implications for palliative care relating to the current economic crisis:

It is feared that the economic crisis will result in a slowing-down of the evolution in palliative care on both a clinical and research basis.

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Bulgaria¹

NATIONAL ASSOCIATION

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|--|-----------------------|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 5 |
| Home palliative care support team | 15 |
| Mixed palliative care support team | 8 |
| Palliative care units in tertiary hospitals | 0 |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 22(n/a) |
| Day hospice/day care centre | 4 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Alexandrova, S. Hospice care - management and ethics (2005, 165 pages);
- Present legislation and medical documents;
- <http://www.nsi.bg/otrasal.php?otr=22&a1=510&a2=511&a3=512#cont>

Additional comments:

- There are five hospital palliative care support teams in wards/sectors at the five Cancer Centers in the following districts: Vratza, Veliko Tarnovo, Russe, Shumen and Varna.
- In Bulgaria, the volunteer hospice team is not popular and there is no such practice; however, there are not enough initiatives or information on this issue. At present, the problem is that there is no regulation in the Bulgarian legislation relating to voluntary and unpaid labour and there is no legal definition of voluntary and unpaid labour in the tax and insurance rules. Therefore, there is no clear mechanism for reimbursement of voluntary work or expenses.

- The main problems in Bulgarian palliative care wards/sectors are: psychological burden on the staff; limited experience and skills in palliative care; limited finance for medical care - only 20 days care per six months is guaranteed from the National Health Insurance for terminally-ill cancer patients.
- Hospices were legally defined as "health institutions" in 1999 but following this development relied mainly on private initiatives (mostly home care). The average length of home care is less than two months and the main reason for ceasing home care is financial; the care is usually provided by nurses and centred on the application of medications and pain and symptom control.
- The most important legal act that regulates hospices is the Law on Healthcare Institutions. Hospices providing home care are private and patients therefore have to pay for palliative care services. There is a registration regime for the establishment of hospices, which is similar to the registration regime for healthcare institutions for domiciliary care. The establishment of hospices as a legal entity (commercial companies or co-operatives) is based on the Commercial Law and the Law on Co-operatives. After registration in the District Healthcare Center under the Law on Healthcare Institutions, the hospice may legally provide healthcare.
- Eight of the 22 hospices in Bulgaria provide both inpatient palliative care and home-based palliative care for terminally-ill patients. In order to provide this combination of care, a number of financial and professional issues have to be addressed. According to the Law on Healthcare Institutions, the fundamental financing of all healthcare institutions comes from the National Health Insurance Fund, State and municipal budgets, voluntary health insurance funds, and donations from national and foreign legal and natural persons. From 01.01.2012, hospices were able to use financial resources from the National Health Insurance Fund on Clinical path 297 for inpatient palliative care for terminally-ill cancer patients. According to this legislation, hospices registered by the Law on Healthcare Institutions and according to the Commercial Law can receive finances for palliative care for terminally-ill cancer patients for 20 days of inpatient care within six months.

- Hospices are the main providers of palliative care and are mentioned in Article 28 of the Law on Healthcare Institutions. The legal regime of establishing, functioning, financing and taxation of hospices is regulated by a number of Acts. Hospices as commercial companies and cooperatives are subject to Bulgarian tax laws. They are obligated to pay tax in accordance with provisions in the Law on Corporate Income Tax Levying. They are subject to advance taxation according to the Law on Local Taxes and Fees and the Law on Value Added Tax. To be admitted to a hospice, a patient needs to be recommended by a doctor from the healthcare institutions for primary help. All the necessary documents for receiving finances on palliative care for cancer patients from the National Healthcare Insurance Fund are described in the clinical path 297.
- There are four day care centers – two are based at home care hospices and two are based at hospices for inpatient palliative care. Day care centers have a team of four nurses, two psychologists, two social workers, and one kinesiology therapist. During the day, two nurses and one social worker care for patients. When it is necessary, a physician and two psychologists provide consultation for patients. Usually, patients stay at day care centers for a minimum period of one month and a maximum period of six months. This form of hospice care is usually paid for by the family of the patient or by donations.

Palliative care services for children:

There is no information available at this time.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

- 1992** The first palliative care training course is provided with the help of the Open Society Institute and the Soros Foundation.
- 1994** An outpatient consulting team specialised in palliative care nursing for cancer patients is organised in Sofia.
- 1996** The centre for controlling cancer pain is founded at the Cancer Hospital (Pleven).
- 1997** The centre for controlling cancer pain is founded at the Cancer Hospital (Vratsa).
- 1998** The first inpatient hospital-based palliative care department is opened at Vratsa.
- 1998** The first pain centre for chronic non-malignant pain is established in Sofia.
- 2001** The National Health Insurance Fund creates a clinical pathway – palliative care for terminal cancer patients – reimbursing 20 days stay in hospital for six consecutive months. Some hospitals create their own teams in order to have a contract with the National Health Insurance Fund.
- 2002** A new law and decree regulating the prescribing, shipping, storing and handling of opioids and other controlled drugs comes into operation, leading to the introduction of many new drugs into everyday practice.

(...)

(...)

- 2002** A new law and decree regulating the prescribing, shipping, storing and handling of opioids and other controlled drugs comes into operation, leading to the introduction of many new drugs into everyday practice.
- 2003** The Bulgarian Association of Palliative Care is founded.
- 2003** Medical College (Vratsa), Cancer Hospital (Vratsa), Medical College (Den Helder, Holland), and the MARTA foundation start a project entitled "Development of palliative care in Bulgaria". Its main target is to prepare future teachers in palliative care at four medical colleges in Bulgaria and to prepare a textbook in palliative care nursing for Bulgaria and Holland.
- 2003** The Bulgarian chapter of the International Association for the Study of Pain (IASP) is established.
- 2004** The first national palliative care conference with foreign participants dedicated to pain control takes place in Bansko.
- 2004** It is established that several private hospices are working without a contract with the National Health Insurance Fund because of some legal obstacles; within the Hospital Law such structures do not exist as hospices. In order to continue their activities some 'hospices' became part of other hospitals.
- 2004** A group of specialists working in the field of palliative care creates national palliative care guidelines (upon a written order from the Minister of Health).
- 2004** The Bulgarian Association of Palliative Care mark the publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organization of palliative care) by translating the document into Bulgarian. As a result of this, the Bulgarian Ministry of Health authorizes a committee to create Bulgarian standards of palliative care.
- 2005** A meeting of the IASP takes place in Sofia.
- 2005** Medical College (Vratsa) provides the first Master's degree in palliative care (officially approved by the Bulgarian Ministry of Education, Ministry of Health and Bulgarian Medical Academy for Postgraduate Nursing).

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

The National Law of Health (August 2011) states that each patient with an "incurable disease" has the right to palliative care and adequate symptom control; it also states that euthanasia is prohibited in Bulgaria. In the Law of the Medical Institutions (2010), the former regional cancer hospitals are transformed into Comprehensive Cancer Centres that are obliged to perform palliative care and symptom control for cancer patients; hospices are recognized as medical institutions (not as social ones) and this change allows the National Health Insurance Fund to recognize hospices as partners. There is a necessity to harmonize national legislation with European Union (EU) legislation.

Overall progress in hospice and palliative care:

Hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: There are dedicated beds for palliative care in all nine Comprehensive Cancer Centres. There are newly-developed palliative care teams in some hospitals (for example, Tokuda hospital, Sofia).
- Nursing homes: According to the law in Bulgaria, there are no nursing homes; however, there are homes for long-term care run by the Ministry for Social Affairs.
- Residential homes for the elderly: As for nursing homes.
- Other community settings: There is no information available at this time.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

To date, the National Health Insurance Fund only recognizes and funds palliative care for cancer patients; other chronic conditions are not recognized.

Perceived barriers to the development of hospice and palliative care:

- Lack of knowledge and education about palliative care;
- Lack of a critical mass of educated healthcare professionals;
- Lack of public awareness about the potential benefits of palliative care and the palliative care approach;
- Lack of public pressure to consider palliative care as a fundamental human right enshrined in legislation;
- Lack of funding due to the economic crisis, restricted finances, a relatively poor society with no tradition in charitable donation, and difficulties in cooperating with similar organizations abroad.

Perceived opportunities for the development of hospice and palliative care:

- Changes in legislation – palliative care as a human right;
- Possibilities to develop new educational programs in the field of palliative care;
- EU membership and new possibilities for combining actions and projects with partners from other EU countries.

Other issues relevant to the development of hospice and palliative care:

There is no information available at this time.

Vitality

THE VITALITY OF PALLIATIVE CARE**National Associations of Palliative Care:**

The Bulgarian Association for Palliative Care (Българска Асоциация по Палиативни грижи) was formed in 2001 and is representative of the whole country (www.bapc-bg.org).

Directory or catalogue of palliative care services:

There is no directory or catalogue of palliative care services although each registered hospice in Bulgaria has its own website.

Congresses, scientific meetings or scientific journals in palliative care:

In 2011, there was an annual meeting of the Bulgarian Association for Palliative Care with a representative of the World Health Organization at the Cancer Center in the district of Vratza.

Palliative care research capacity:

Dr Nikolay Radev Yordanov (Cancer Center, Vratza).

Palliative care collaboration:

- There is no official information available relating to World Hospice and Palliative Care Day, twinning or other forms of palliative care collaboration; such practice is not popular or well-established in Bulgaria.
- A pioneer is Hospice "Milosardie" established by Donka Paprikova in 1989.

Worldwide palliative care alliance level of development:

Group 2 (capacity-building activity): there is capacity for the development of palliative care in Bulgaria in conjunction with reforms to the Bulgarian Health-care System. There is no separate structure that works actively on the development of hospice care in Bulgaria.

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006**General developments in palliative care education and training initiatives:**

There is no information available at this time.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Education in palliative care is not included in medical school curricula, although it is included as a part of student education in oncology.
- Nursing: There is no information available at this time.
- Social work: There is social work education relating to elderly and disabled terminally-ill patients
- Other professions: There is no information available at this time.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: Palliative and end-of-life care are part of postgraduate training in oncology.
- Nursing: Palliative and end-of-life care are part of the postgraduate curricula for nurse training in oncology.
- Social work: There are postgraduate training courses for social workers and psychologists.
- Other professions: There is no information available at this time.

Translation of palliative care documents or other materials:

There is no information available at this time.

Initiatives to develop healthcare professional leadership in palliative care:

There is no information available at this time.

Officially recognized medical certification:

There is no officially recognized medical certification but there are palliative care courses for nurses and several topics about the main problems and definitions relating to palliative care on the agenda of physicians specializing in medical oncology; the treatment of pain is also well represented on these courses. The courses are not a part of the accreditation process for physicians specializing in palliative care or palliative medicine.

Capacity of palliative care workforce training in Universities and Medical Schools:

- Bulgaria has four medical universities and one medical faculty at the University of Sofia "St. Kliment Ohridsky".
- The work in psycho-oncology undertaken by Irena Jivkova Hadjijska was supported by her colleagues in clinical social work and psycho-oncology in the United States and Eastern Europe.
- There are no academic teachers specialized in palliative care.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- There are WHO step II and III opioids – in slow release and injectable release forms – codeine, tramadol, morphine, oxycodone and fentanyl. Methadone is only used in substitution therapy.
- As Bulgaria is only a small market, many pharmaceutical companies are not interested in selling their products in the country.

Developments/opportunities/barriers relating to the accessibility of essential medications:

Opioids are free of charge for cancer patients with no limit to the prescribed amount.

Developments/opportunities/barriers relating to the affordability of essential medications:

Opioids are difficult to afford for non-cancer palliative care patients.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

There is no information available at this time.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- The most important legal or policy changes affecting the development of hospice and palliative care in Bulgaria are the changes in the health law proclaiming the right of every patient with "incurable disease" to receive quality palliative care and adequate symptom control.
- The prohibition of euthanasia in Bulgaria has been very important.

The impact of these policy changes and ways in which they have been important:

For the first time it is enshrined in legislation that each Comprehensive Cancer Centre is obliged to provide palliative care and symptom control for all cancer patients who need it.

Development of a national palliative care consensus:

- Palliative care standards are under construction.
- There is a palliative care pathway for terminally-ill cancer patients.
- Palliative care is recognized by the Bulgarian Cancer Society as an essential part of quality cancer treatment and is included in the National Standards of Cancer Treatment and Care.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

A conference to develop the national plan for prevention, screening, diagnosis and treatment of cancer took place in Sofia in 2011; palliative care was recognized as an essential part of anti-cancer treatment and a partnership with WHO was established in Vratsa where the action plan was passed to the Ministry of Health and the Ministry of Labour and Social Affairs for implementation.

Development of an advocacy framework for integrating palliative care into the health care system:

Changes to the various laws have resulted in palliative care becoming integrated as a standard part of anti-cancer treatments.

Strategies to improve political awareness and government recognition of palliative care:

There is no information available at this time.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

The only funding of palliative care is governmental - via the Ministry of Health and Ministry of Labour and Social Affairs (National Health Insurance Fund).

Involvement with the European Union in relation to hospice and palliative care initiatives:

As a member state of the EU, Bulgaria is obliged to implement EU initiatives in the field of palliative care.

Development of initiatives framing palliative care as a 'human right':

The right of every patient with "incurable disease" to quality palliative care is written in Bulgarian Law of Health articles 95 and 96 (<http://lex.bg/laws/ldoc/2135489147>).

General legislation relating to palliative care:

Bulgarian Law has defined hospice within the Law on Healthcare Institutions; hospices are thus allowed to receive finances for palliative care for terminally-ill cancer patients from the National Healthcare Insurance Fund.

Published national documents relating to palliative care standards and norms:

- Methodical Instruction No. 3 from March 29, 2000 states that the activities of hospices target "mainly terminally-ill patients".
- Palliative care standards are in process: Clinical Path 297 is an algorithm for treatment and satisfies all the requirements of the National Healthcare Insurance Fund for financing palliative care for terminally-ill cancer patients.

National Plan or Strategy of Palliative Care:

There is no information available at this time.

National Cancer Control Strategy:

There is a National Cancer Control strategy where prophylaxis is the main activity; palliative care is not considered as a priority and the only statistic contained in the strategy suggests that every year, approximately 2,000 cancer patients require palliative care.

The National Law of Health (2011) states that each patient with an "incurable disease" has the right to palliative care and adequate symptom control; there are newly-developed palliative care teams in some hospitals

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy but palliative care is not a priority in this strategy.

National Primary Health Care Strategy:

There is a National Primary Health Care Strategy in which palliative care is presented as a topic that requires an increase in knowledge and development of skills.

Designated policy maker for the delivery of palliative care services:

The government has a designated policy maker for the delivery of palliative care services and there are several publications, surveys and books published in Bulgarian on hospice care (mainly at the Departments of Social Medicine at the Medical Universities and the Open Society Institute in Sofia).

Department of Health specific responsibility for the delivery of palliative care services:

New legislation and healthcare reforms include the necessary requirements and conditions for the development of hospice care and palliative medicine in Bulgaria.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- Opioid legislation: The rules for prescribing strong opioids are formulated according to the Law of Narcotic Drugs and Order 40 for defining medical activities guaranteed by the National Healthcare Insurance Fund. A medical commission at the specialized hospitals prescribes opioids and the patient can receive them free of charge from the hospital pharmacy in person.
- Pain guidelines: There are WHO guidelines for pain treatment and rules described in the Clinical path 297 "Palliative Care for Cancer Patients".

Funding of palliative care services:

- Full payment is required for consultation: the National Healthcare Insurance Fund does not include finances for out-patient consultations.
- No payment is required for 20 days inpatient palliative care per six months when a cancer patient is terminally ill.

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

There is no information available at this time.

Major public discussion, debate or controversy about hospice and palliative care:

There was a major debate about hospice and palliative care when legalisation for euthanasia in Bulgaria was proposed by the socialist Lyuben Kornezov.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

There is no information available at this time.

Hospice or palliative care 'success' stories:

Comprehensive Cancer Centre Vratsa was accredited by ESMO 2011 as a designated centre integrating oncology and palliative care (<http://www.esmo.org/education-research/designated-centers-of-integrated-oncology-and-palliative-care/accredited-centers-list.html>)

Initiatives seeking the legalisation of euthanasia or assisted dying:

Only one initiative seeking the legalisation of euthanasia or assisted dying has been proposed (by the former communist Lyuben Kornezov – see above) but it was completely rejected by Bulgarian society; suicide is considered a sin by Bulgarian orthodox morality.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

According to the recently-developed action plan, the Comprehensive Cancer centre in Vratsa will become a WHO collaborating centre for development of palliative care in Bulgaria by implementing the Catalonia model for middle-income countries.

Most significant issues facing hospice and palliative care in the next three years:

Education of the medical community, policy makers and society about the benefits of the palliative care approach to improve the quality of life of patients and their families: it saves money and resources of society and is a human right for everyone.

Implications for palliative care relating to the current economic crisis:

Lack of funding and the necessity of having to compete for limited resources with other medical specialties.

References

Gancheva A. 1994. "National reports Europe: Bulgaria". Eur J Palliat Care;1(2):N1.

In the Law of the Medical Institutions (2010) the former regional cancer hospitals were transformed into nine Comprehensive Cancer Centres that are obliged to perform palliative care and symptom control for cancer patients

Under the same legislation, hospices are now fully recognized as medical institutions (not as social ones) and this change allows the National Health Insurance Fund to recognize hospices as partners

Croatia¹

NATIONAL ASSOCIATION

Dom zdravlja Primorsko-Goranske županije Project

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Ivanka Kotnik, PRESIDENT OF ASSOCIATION/ VOLUNTEER -PHYSICIAN SINCE 1999 (EMPLOYED IN INSTITUTION FOR EMERGENCY MEDICINE IN THE CITY OF ZAGREB)

KEY CONTACT

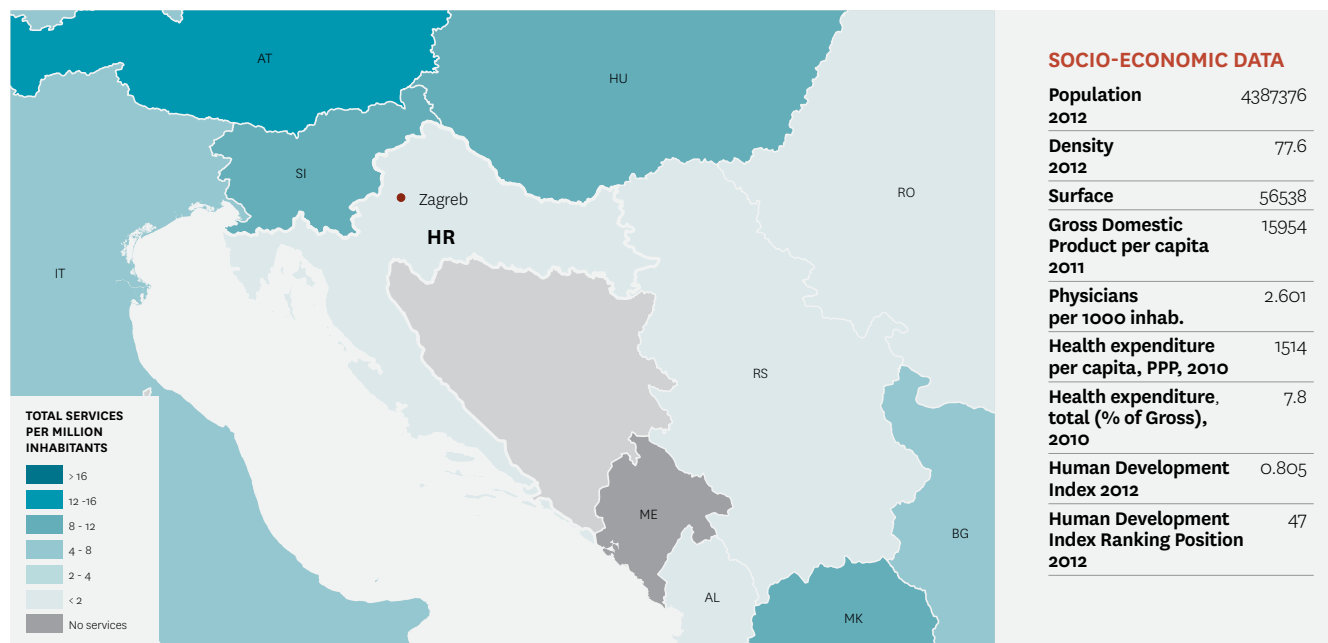
Matija Rimac President of Center/Leader of home hospice team, volunteer -physician since 2000

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 4 |
| Hospital palliative care support team | 0 |
| Home palliative care support team | 4 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 0 |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 0 |
| Day hospice/day care centre | 1 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Personal estimates/estimates provided by experts.
- Presentation dr devčić, 18.19.06.2012: "Advising about palliative care," Šalata, University of Medicine

Additional comments:

- A mobile palliative care team was established in Zagreb in 2012.
- There are four volunteer hospice teams (three of these are based in Zagreb - doctors, nurses, psychologists, physiotherapists) - no-one receives any payment for their services.
- There are three home palliative care support teams in Rijeka City and one in Pula (Istria) funded by the regional government.
- There is one day center in the General Hospital in Koprivnica.
- Medical and non-medical volunteers from the Croatian Association of Hospice Friends visit patients in their own home.

Palliative care services for children:

There is no information available at this time.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

- 1994** The Croatian Society for Hospice/Palliative Care is founded.
- 1994** The First Symposium on Hospice and Palliative Care is held in Zagreb. It is introduced by Dr. Nigel Sykes, from St Christopher's Hospice, London.
- 2000** The Croatian Association on Pain Treatment (Croatian Medical Association) is founded.
- 2002** The Regional Hospice Centre in Zagreb is opened by The Croatian Association of Hospice Friends.
- 2002** David Oliver, Medical Director of the Wisdom Hospice in Rochester, England, is elected as visiting Professor of the Medical Faculty, University of Zagreb.
- 2003** Kathleen Foley (Open Society Institute, New York) is elected as a guest Professor of Medical Faculty, University of Zagreb.

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- The establishment of the first two mobile teams of palliative care in the Rijeka region in 2008.
- The establishment of the "Friends of Hospice" Association in Zagreb.
- Equipping the building of a new hospice in Rijeka.

Overall progress in hospice and palliative care:

Hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: The establishment of a division of palliative care
- Nursing homes: The Croatian Association of Hospice Friends visit nursing homes twice per week.
- Residential homes for the elderly: There is no information available at this time.
- Other community settings: Palliative care in Rijeka is organized in the form of mobile teams who visit the patient in their home. The teams consist of physicians and nurses; the number and frequency of visits are not limited and depend on the patient's condition and wishes.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

Most patients requiring palliative care are in the advanced stages of malignant disease. However, palliative care is also provided for all people suffering from chronic disease at the end of life; for example, neurological disorders (stroke, multiple sclerosis), dementia, heart failure, chronic disease of the kidneys and lungs.

Perceived barriers to the development of hospice and palliative care:

- Lack of finance.
- Absence of a legal Act on hospice care.
- There is no specialization in palliative medicine.

Perceived opportunities for the development of hospice and palliative care:

- State funding.
- The systematic education of employees.
- Opening new hospice institutions.
- Raising awareness about volunteering.

Other issues relevant to the development of hospice and palliative care:

There are no other issues that have been relevant to the development of hospice and palliative care in Croatia.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

There are two national associations of palliative care: the Croatian Association for Palliative Medicine (hrvatsko društvo za palijativnu medicinu - previously Croatian Association of Hospice and Palliative Care since 1994), which was formed in 2009 and is representative of the whole country (www.palijativa.org); and the Center for Palliative Care and Medicine (Centar za palijativnu skrb i medicinu), which was also formed in 2009, and is representative of the whole country (www.cpsm.hr).

Directory or catalogue of palliative care services:

There is no information available at this time.

Congresses, scientific meetings or scientific journals in palliative care:

The Croatian Congress for Palliative Care is held bi-annually; in 2006 and 2008 approximately 100-200 people attended on each occasion (no information available for 2010).

Palliative care research capacity:

There is no information available at this time.

Palliative care collaboration:

- Zagreb is the center for coordination of palliative care activity: a database of all people and organizations involved in palliative care has been compiled in Zagreb.
- Pioneers in palliative care include: the Center for Palliative Care and Medicine; the Croatian Association for Palliative Medicine whose activities commenced in 1994 under the leadership of Professor Jušić as the Croatian Association of Hospice and Palliative Care. This group of people (physicians, nurses, psychologist, and volunteers - all enthusiasts) were pioneers in palliative care in Croatia. The Center for Palliative Care and Medicine and the Croatian Association for Palliative Medicine both originated from this group.
- World Hospice and Palliative Care Day is promoted and celebrated as "Svjetski dan hošpicija i palijativne skrbi" and concerts or presentations about palliative care are organized. For example, the Center for Palliative Care and Medicine arranged a concert by the famous Croatian opera singer Ivanka Bolljkovac (in the Museum of Art and Craft); the Croatian Association for Palliative Medicine organizes lectures about palliative care during this time.

Worldwide palliative care alliance level of development:

3a (Isolated palliative care provision) – the provision of palliative care is still based on the enthusiasm of a relatively small group of people. There are a number of palliative care initiatives but they are not adequately supported by the Croatian government. Funding of palliative care is a serious problem, and there is insufficient education and training about the discipline (especially in the area of primary care).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

Since 1994, a number of healthcare professionals have received education and training in palliative care in UK, Austria and Poland.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: There is only a basic knowledge of palliative care in under-graduate medical education.
- Nursing: There is no information available at this time.
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: There is only a basic knowledge of palliative care in post-graduate medical education.
- Nursing: There is no information available at this time.
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Translation of palliative care documents or other materials:

A small number of palliative care documents or other materials have been translated in Croatian.

Initiatives to develop healthcare professional leadership in palliative care:

There are no initiatives to develop healthcare professional leadership in palliative care in Croatia.

Officially recognized medical certification:

There is no officially recognized medical certification in Croatia.

Capacity of palliative care workforce training in Universities and Medical Schools:

There are four medical schools in Croatia (in Zagreb, Split, Rijeka, and Osijek) and six medical schools for nurses but none have a curriculum of palliative medicine. There are no professors of palliative medicine in Croatia.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- Previously, opioids were only available on a parenteral basis, but now most forms of opioids are available.
- The list of medications which are available in Croatia needs to be expanded.
- A barrier to the availability of essential medicines is that many are imported from abroad.

Developments/opportunities/barriers relating to the accessibility of essential medications:

- Medicines that are not on the list of essential medicines can be prescribed (under special circumstances).
- A barrier to the accessibility of essential medications in Croatia is insufficient financial resources.

Developments/opportunities/barriers relating to the affordability of essential medications:

The patient must pay for medicines that are not on the list of essential medicines; if they are unable to do so, they will not have access to them (not applicable to palliative care patients).

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

There is no information available at this time.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

Most opioids are on the list of essential medicines and available to those who require palliative care.

Initiatives that consider access to essential medication as a legal and human right:

There are no initiatives in Croatia which consider access to essential medication for pain and symptom management as a legal and human right.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

Healthcare legislation in the area of palliative care is incomplete. The Ministry of Health and Croatian Health Insurance Institute have failed to develop legislation to establish standards for the provision of palliative care at a professional level.

The impact of these policy changes and ways in which they have been important:

There is no information available at this time.

Development of a national palliative care consensus:

There is no information available at this time.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

There is no information available at this time.

Development of an advocacy framework for integrating palliative care into the health care system:

There is no information available at this time.

Strategies to improve political awareness and government recognition of palliative care:

There is no information available at this time.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

- Project Dom Zdravlja Primorsko-Goranske županije provide palliative care in the cities and districts of Rijeka County;
- The Croatian Health Insurance Institute provides funding for home-based palliative care.

Involvement with the European Union in relation to hospice and palliative care initiatives:

There is no information available at this time.

Development of initiatives framing palliative care as a 'human right':

There is no information available at this time.

General legislation relating to palliative care:

Legislation relating to palliative care was published in Narodne Novine in 2003 (Act 81, 2003) that enables palliative care institutions to be developed.

Published national documents relating to palliative care standards and norms:

There is no information available at this time.

National Plan or Strategy of Palliative Care:

There is a National Plan of Palliative Care in process.

National Cancer Control Strategy:

There is a National Cancer Control Strategy, produced by the Ministry of Health and the Croatian National Institution of Public Health; the strategy focuses on the prevention, early detection, and treatment of cancer, but also contains an explicit reference to palliative care provision and highlights the need to develop palliative care services in Croatia (Hrvatski Casopis Za Javno Zdravstvo, vol.4, no.13., 07.01. 2008).

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy in Croatia: the Croatian National Program for HIV/AIDS Prevention (2005-2010). However, the strategy focuses predominantly on the epidemiology of HIV/AIDS, prevention, behaviour and education and has no explicit reference to the provision of palliative care.

National Primary Health Care Strategy:

The National Primary Health Care Strategy is a fundamental part of the National Strategy of Healthcare Development Act (2012-2020): Act 58 of the Constitution of the Republic of Croatia states that one of the primary aims of healthcare is the provision of palliative care for terminally-ill patients (www.zdravlje.hr, 10.07.2012, www.hzzo-net.hr, NN150/08).

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

The Department of Health has specific responsibility for the delivery of palliative care services in Croatia (Croatia will become a member of the EU in July, 2013).

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- Opioid legislation: A standard process is in place for the prescription of opioids that is regulated by the Rule for Medicine Grouping and Prescriptions (NN21/10) Opioids are available by special prescription and recorded double receipt; the person responsible for the prescription process is a general practitioner (www.hzzo-net.hr)
- Pain guidelines: A document entitled 'Pain' was produced by the Croatian Association for Pain (2000 copies) and is available online: www.mjerenje-boli.net; www.hdlb.org

Funding of palliative care services:

No payment is required for palliative care consultation, hospitalisation or medications in Croatia.

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

Information about mobile palliative care teams and the opening of hospices has been provided in the community.

Major public discussion, debate or controversy about hospice and palliative care:

There has been some public discussion and debate about hospice and palliative care.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

Public forums to broaden awareness and understanding of hospice and palliative care have been organized.

Hospice or palliative care 'success' stories:

There are no hospice or palliative care 'success' stories in Croatia at the present time.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There are no initiatives seeking the legalisation of euthanasia or assisted dying in Croatia at the present time.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

There should be a mobile palliative care team in every local community to provide care for patients at the end-of-life (funded by the Croatian Health Insurance Institute); hospices should be established in every large region of Croatia.

Most significant issues facing hospice and palliative care in the next three years:

The most significant issues facing hospice and palliative care in the next three years are: insufficient funding; lack of legislation for establishing hospices; and lack of an educated and trained workforce.

Implications for palliative care relating to the current economic crisis:

In relation to the current economic crisis, the challenges for palliative care in Croatia are: an inability to organize mobile palliative care teams; insufficient funds for appliances and equipment in hospices; and (recently) an increasing number of people who do not receive appropriate care.

There has been some increase in State funding for palliative care. New mobile palliative care teams were established in 2008 and in 2012 and a new hospice has been equipped and built in Rijeka

References

Jusic A, Persoli-Gudelj M. 2002. "Croatia: development of a hospice movement and palliative care". *J Pain Symptom Manage*. 2002;24(2):180-2."

Oliver D, Murtagh F, Jusic A. 2005. "Palliative care in Croatia - an international collaboration". *Eur J Palliat Care*;12(3):127-129."

Đorđević V, Braš M, Milunović V, Brajković L, Stevanović R, Polašek O. February 2011. "The founding of the Centre for Palliative Medicine, Medical Ethics and Communication Skills: a new step toward the development of patient-oriented medicine in Croatia". *Croat Med J*; 52(1):87-8.

Brkljčić M, Mavrinac M, Sorta-Bilajac I, Bunjevac I, Cengiđ T, Golubović V, Sustić A. June 2009. "An increasing older population dictates the need to organise palliative care and establish hospices". *Coll Antropol*;33(2):473-80.

Cyprus¹

NATIONAL ASSOCIATION

The Cyprus Association of Cancer Patients and Friends [PASYKAF]

ΠΑΓΚΥΠΡΙΟΣ ΣΥΝΔΕΣΜΟΣ
ΚΑΡΚΙΝΟΠΑΘΩΝ ΚΑΙ ΦΙΛΩΝ
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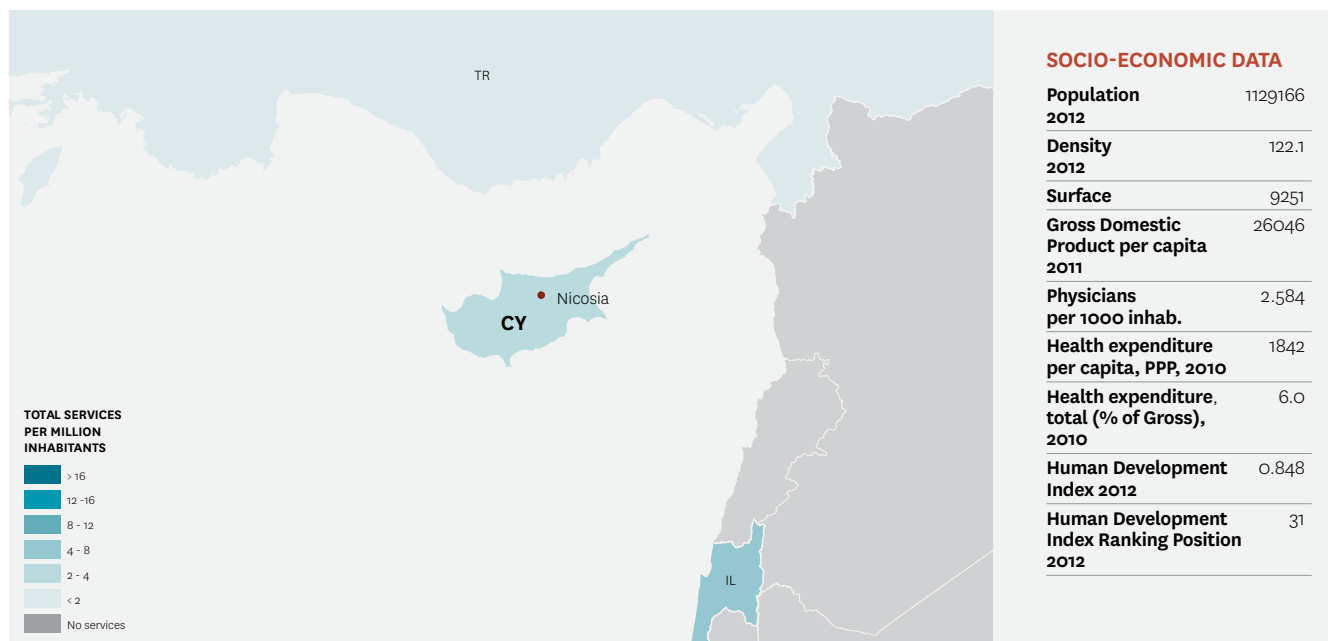
KEY CONTACT

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sophia.nestoros@anticancersociety.org.cy

¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 0 |
| Home palliative care support team | 2 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 0 |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 1 (15) |
| Day hospice/day care centre | 9 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Sophia Nestoros
- The Cyprus Anti-Cancer Society
- www.anticancersociety.org.cy

Additional comments:

There are two home palliative care support teams for the whole island and they are for cancer patients only – the services are provided by two non-governmental organizations (NGOs); The Cyprus Association of Cancer Patients and Friends (PASYKAF) and The Cyprus Anti-Cancer Society.

Palliative care services for children:

There is no information available at this time.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

- 1971** The Cyprus Anti-Cancer Society is founded. It offers inpatient care (hospice care), a home care service, day care, psychosocial support and lymphoedema clinics in all districts by health professionals trained in palliative care.

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- The cancer control plan contains a section dedicated to palliative care. The plan has not yet been disseminated (or even publicly announced) but work commenced on it in January 2011. Unfortunately, the plan has no official budget and is therefore more like a 'wish list'. However, it is the first time that the government of Cyprus has acknowledged palliative care as a separate part of the cancer continuum. Up until this time, NGOs were the only health professionals involved in palliative care; the EU has put pressure on countries to develop a cancer control plan and this is the reason that a plan has been developed.
- As a result of the cancer control plan, the Ministry of Health has become more sensitised to the need for palliative care within the health system and that it could in fact save money rather than increase their budget. In December 2011, Dr Frank Ferris and his team from San Diego Hospice were invited to come to Cyprus by the government and for the first time health professionals from outside the discipline of oncology were educated about pain control and palliative care. This was an important initiative, as there are now role models throughout government hospitals discussing palliative care, patient's rights and pain control. Also in December 2011, a four-day course on paediatric palliative care was provided by the Middle East Cancer Consortium (MECC) that has had some impact; there will be a follow-up course in 2012 to provide the opportunity to present changes that have been made in the area of paediatric palliative care.
- In 2006, a strong opioid (Oxycodone) became available to purchase for the first time in a private pharmacy in Cyprus. Previously all opioids had to be purchased from government hospitals and were only accessible from Monday to Friday. Pain control for patients is much improved due to this increased access; this is especially so for post-surgery patients (operated on by private surgeons) waiting for biopsies as previously only oncologists were allowed to prescribe opioids. Unfortunately, there are still only approximately 40 pharmacies in Cyprus that stock opioids (from approximately 500 pharmacies in total).

Overall progress in hospice and palliative care:

Hospice and palliative care has improved (slightly).

Development of hospice and palliative care in different health and social care settings:

- Hospitals:** A 30-hour course in the principles and practice of palliative care was attended by 40 participants who disseminated this information throughout different areas of the hospital system. A questionnaire was sent to the Ministry of Health to monitor this group: firstly, to identify those healthcare professionals who were interested in learning more about palliative care and becoming increasingly involved in delivery of services; and secondly, to discover any barriers they faced when returning to their workplace when attempting to implement what they had learnt. Through this process, future leaders of palliative care may be identified (when the budget allows it).
- Nursing homes:** No developments
- Residential homes for elderly:** No developments

- Other community settings:** The only development has been that for the first time oncologists are beginning to realise the importance of home-based palliative care and the continuity of care between different settings. This improved communication has resulted in a better standard of care for the patient; unfortunately this is not applicable to all areas of oncology and much work is still required in this area.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

The education courses offered in December 2011 were the first steps to achieve the goal of palliative care becoming part of the health care continuum for all chronic illnesses. Paphos hospice now offers beds for all patients with chronic illness at the end of life; there are no other NGOs offering palliative care for cancer patients.

Perceived barriers to the development of hospice and palliative care:

(i) Financial: If there were no financial constraints, the Ministry of Health would be interested in developing palliative care (as the population ages and the cost of care increases accordingly). If there were no financial constraints, PASYKAF would operate 24 hours per day/7 days per week but due to budget constraints this is not possible (ii) Government commitment: many NGOs have appeared in Cyprus and coordination and standardisation of the services offered throughout the island is required. All these NGOs need to be coordinated by the Ministry of Health (iii) Lack of education (iv) Opiophobia.

Perceived opportunities for the development of hospice and palliative care:

- There are healthcare professionals in Cyprus with palliative care experience. A basic course in palliative care could be offered to healthcare professionals in hospitals, but the government would need to allow them to take some form of educational leave. Some discussion around palliative care education has already taken place with the Ministry of Health and NGOs.
- Pharmaceutical services organised a meeting on 29th Feb 2012 to discuss a range of pain medication, opioid dosages and routes currently not available/practiced in Cyprus (or only available privately).
- Cyprus has been offered four places for the Fellowship Program at San Diego Hospice funded partly by San Diego Hospice, the National Cancer Institute and organizations in Cyprus that employ the participant. Places on this Fellowship Program have currently been accepted by three doctors in Cyprus and a participant for the fourth place is currently under negotiation; it is hoped that those attending the program will become role models and teachers in palliative care in Cyprus.

Other issues relevant to the development of hospice and palliative care:

Cyprus is involved in the ATOME project (to improve availability and accessibility of opioids in 12 target countries) and for the first time will be working with professionals from harm reduction. The project provides an opportunity for individuals to set goals and targets which normally would not be possible due to daily work commitments. The follow-up conferences ensure that the momentum continues; the international expertise provided is also important as local experts are often not afforded credibility.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- The Cyprus Anti-Cancer Society (ΑΝΤΙΚΑΡΚΙΝΙΚΟΣ ΣΥΝΔΕΣΜΟΣ ΚΥΠΡΟΥ) was formed in 1971; it has a website (www.anticancersociety.org.cy) but is not representative of the whole country.
- The Cyprus Association of Cancer Patients and Friends (PASYKAF) (ΠΑΓΚΥΠΡΙΟΣ ΣΥΝΔΕΣΜΟΣ ΚΑΡΚΙΝΟΠΑΘΩΝ ΚΑΙ ΦΙΛΩΝ (ΠΑΣΥΚΑΦ)) was formed in 1986; it does not have a website and is not representative of the whole country.

Directory or catalogue of palliative care services:

There is no directory or catalogue of palliative care services in Cyprus.

Congresses, scientific meetings or scientific journals in palliative care:

The congress "Palliative Care Principles in Practice" is held annually, attracting approximately 50 participants.

Palliative care research capacity:

There is no information available at this time.

Palliative care collaboration:

- The two national palliative care associations of Cyprus have significant collaborations with a number of organizations; for example, MECC, European Association for Palliative Care (EAPC), San Diego Hospice, etc. A number of Cypriot healthcare professionals (nurses, physicians, psychologists, etc.) take part in congresses and seminars in both Europe and the USA.
- The development of palliative care in Cyprus is due to pioneering initiatives by the two national palliative care associations.
- A number of social events are organized to celebrate World Hospice and Palliative Care Day; for example, use of the Life before Death video to educate the public about human rights and motivate relevant discussion.

Worldwide palliative care alliance level of development:

4A (Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- The paediatric palliative course provided by MECC in December 2011;
- The 30-hour course in palliative care provided by representatives from San Diego Hospice in December 2011;
- The MSc in nursing at Nicosia University contains a pain module as part of the curriculum. There are also a small number of "low key" palliative care initiatives such as lectures to small groups of surgeons and BSc students, in-service hospital education, etc.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: No developments.
- Nursing - Pain management remains disseminated within the syllabuses of geriatrics, community medicine, pain control in oncology nursing etc. but it is only of a few hours duration and is not well-focused. It is hoped that discussion within the ATOME project will examine this problematic area further and develop some form of standardisation as part of the criteria for nursing council qualification.
- Social work: No developments.
- Other professions: No developments.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: No developments.
- Nursing: Palliative care module in MSc in nursing at Nicosia University.
- Social work: No developments.
- Other professions: No developments.

Translation of palliative care documents or other materials:

The WHO document Ensuring Balance in National Policies on Controlled Substances: Guidance for availability and accessibility of controlled medicines has been translated.

Initiatives to develop healthcare professional leadership in palliative care:

There is no information available at this time.

Officially recognized medical certification:

There is no information available at this time.

Capacity of palliative care workforce training in Universities and Medical Schools:

- There is one medical school in Cyprus and palliative medicine is a mandatory component there.
- There are no professors of palliative medicine in Cyprus.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

Since 2006, all essential medicines have been available to all patients with a chronic illness that have a hospital card (i.e. European National) – doctors in Cyprus just need to prescribe them.

Developments/opportunities/barriers relating to the accessibility of essential medications:

Since 2006, all essential medicines have been accessible to all patients with a chronic illness that have a hospital card (i.e. European National).

Developments/opportunities/barriers relating to the affordability of essential medications:

Since 2006, all essential medicines have been affordable to all patients with a chronic illness that have a hospital card (i.e. European National).

Initiatives to change regulations that may restrict physician or patient access to pain relief:

Previously, private pharmacies had to obtain a licence for every opioid they purchased; this was changed to obtaining an annual licence every year which resulted in approximately 40 pharmacies agreeing to stock opioids.

Initiatives to promote attitudinal change in relation to 'opiophobia':

- A society of Oncology Palliative Care Nurses has been formed.
- Initiatives relating to the International Association for the Study of Pain (IASP).
- The education provided by MECC (in paediatrics) and San Diego Hospice have made health professionals consider the role of pain management in their everyday work practice.
- There have been no specific initiatives to promote attitudinal change in relation to 'opiophobia'.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

All patients with chronic illness have free access to all medication in Cyprus.

Initiatives that consider access to essential medication as a legal and human right:

On 3rd October 2011, following an initiative from MAC (MEPs against cancer), PASYKAF went to the Cypriot Parliament to highlight the needs of cancer patients for pain control and palliative care as a fundamental human right. They returned to Parliament on 17th Oct 2011 to reply to some of the queries posed by government representatives.

The National Cancer Control Plan contains a section dedicated to palliative care; it is the first time that the government of Cyprus has acknowledged the need for palliative care within the health care system and that it could save money

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

When the National Cancer Control Strategy is published, it will become the first document produced by the Ministry of Health that officially acknowledges palliative care.

The impact of these policy changes and ways in which they have been important:

Within the strategy, short, medium and long-term goals have been set. As a part of the strategy, hospital palliative care teams will become an important part of the continuity of care between hospital and home as well as acting as role models in providing palliative care education in community settings (such as residential homes); providing the government commits to this plan, it will make a tremendous difference to the standard of palliative care provided to patients.

Development of a national palliative care consensus:

Standards and frameworks have been developed within the National Cancer Control Strategy.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

Significant meetings have been held with stakeholders and policy makers to develop the National Cancer Control Strategy (but they did not include all stakeholders).

Development of an advocacy framework for integrating palliative care into the health care system:

National Cancer Control Strategy.

Strategies to improve political awareness and government recognition of palliative care:

Meetings have been held with the Ministry of Health on a number of occasions; for example, Dr Frank Ferris (San Diego Hospice, USA) has met with the Minister of Health to discuss palliative care in Cyprus. Unfortunately Ministers often change positions within the government and this can make the situation more difficult. PASYKAF has visited Parliament twice to promote the right of the patient to pain control, palliative care and psychosocial support as human rights.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

There is no information available at this time.

Involvement with the European Union in relation to hospice and palliative care initiatives:

ATOME project.

Development of initiatives framing palliative care as a 'human right':

There is no information available at this time.

General legislation relating to palliative care:

There is no information available at this time.

Published national documents relating to palliative care standards and norms:

There is no information available at this time.

National Plan or Strategy of Palliative Care:

There is no information available at this time.

National Cancer Control Strategy:

The fourth main area of the National Cancer Control Strategy is the provision of palliative care.

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy in Cyprus but it does not contain an explicit reference to palliative care provision.

National Primary Health Care Strategy:

There is no information available at this time.

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

There is no information available at this time.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- Opioid legislation includes the requirement to prescribe the whole amount of opioids in 'words' as well as numbers and from the Bank of Cyprus Oncology Centre; opioids must also be prescribed on a 'rose' coloured prescription form.
- There are no pain guidelines in Cyprus.

Funding of palliative care services:

There is no payment required for palliative care consultation, hospitalisation or medication in Cyprus.

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

Patients and families appear to be less "opiophobic"; this may be because less morphine (stigmatized) is being prescribed in favour of opioids such as Oxycodone and Fentanyl.

Major public discussion, debate or controversy about hospice and palliative care:

There is no information available at this time.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

There is no information available at this time.

Hospice or palliative care 'success' stories:

The Bank of Cyprus Oncology Centre is to send two junior doctors to the 2012 San Diego Hospice International Fellowship Program. Currently 80% of oncology patients are treated in this centre so it is expected that the increased training of these two doctors (one in charge of inpatients and the other working with outpatients and home care) will make a big difference to patient's symptom control and pain management.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is no information available at this time.

In 2006, Oxycodone became available to purchase for the first time in a private pharmacy in Cyprus. Previously all opioids had to be purchased from government hospitals and were only accessible from Monday to Friday

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

Hospice and palliative care is ready to be further developed in Cyprus. There is increased sensitisation and awareness about palliative care and if the financial crisis had not hindered progress, the discipline would have moved forward on many levels. Further progress will have to wait until the NGOs and government are economically stable but the most important thing is that the commitment to progress exists – currently, the focus will have to be on areas that do not cost as much money; for example, the translation of literature on opiophobia, basic courses on pain management, becoming more vocal in the press, and continuing to meet with the Ministry of Health and encouraging them to establish standards that hospice and palliative care centres can work towards, etc.

Most significant issues facing hospice and palliative care in the next three years:

The main focus of organisations is providing home-based palliative care; a pilot programme is being developed that provides 24hr-care and will demonstrate to the government an accurate costing of how much can be saved if patients are able to die at home with the support of home-based palliative care and their family. A commitment must be made to continue to provide education and support within hospitals and private clinics and to become role models and educators in these community settings.

Implications for palliative care relating to the current economic crisis:

The challenges relating to the current economic crisis are that there are many NGOs trying to raise money and as Cyprus only has a small population (that are experiencing salary cuts) they are all severely affected. Organisations are hoping to be able to retain their present staff but unfortunately it will be more difficult to offer new services. Palliative care in Cyprus is likely to remain at a standstill until the current economic crisis ends, but hopefully once it does, the Ministry of Health, the Cypriot public and patients and their families can become sensitised to the concept of palliative care, and (as soon as the budget allows) the National Cancer Control Strategy can be fully enacted.

References

Costello J, Christoforou C. 2001. "Palliative care in a Mediterranean culture: a review of services in the Republic of Cyprus". *Int J Palliat Nurs*; 7(6):286-9.

Malas S. April 2011. "The current status of palliative care in Cyprus: has it improved in the last years?". *J Pediatr Hematol Oncol*; 33 Suppl 1:S47-51.

Some discussion around palliative care education has already taken place with the Ministry of Health and NGOs. Health professionals from outside the discipline of oncology have been educated about pain control and palliative care

Czech Republic¹

NATIONAL ASSOCIATION

Czech Society for Palliative Medicine

Česká společnost paliativní medicíny ČLS JEP

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Additional information provided by:

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 6 |
| Hospital palliative care support team | 2 |
| Home palliative care support team | 4 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 0 |
| Palliative care units in non-tertiary hospitals | 2 (45) |
| Inpatient hospice | 15 (385) |
| Day hospice/day care centre | 9 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

Ondrej Slama (personal experience).

Additional comments:

Many district home care services provide some aspects of palliative nursing and palliative care as a part of their "daily routine" (e.g. pain and symptom management, psychosocial support, counselling).

Palliative care services for children:

There is one paediatric hospital palliative care support team and two paediatric home palliative care support teams in the Czech Republic.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

- 1995** First in-patient hospice opened in Cervený Kostelec.
- 1998** Textbook "Palliative medicine" published by Professor Vorlíček (450 pp.).
- 2003** The Methodical Instructions for Tumor Pain Management is accepted as an obligatory standard by the Society of General Practitioners.
- 2004** The new Medical Education Act is passed. It includes a provision on palliative care and control of pain as a separate medical discipline.
- 2005** The Committee for Palliative Care is initiated by the Ministry of Health.
- 2006** The Committee for Palliative Care is dissolved by the Ministry of Health.

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- Two new hospices have been built and opened;
- Two palliative care units have been opened in long-term care hospitals;
- The attitude towards hospice and palliative care both within the professional community and in the public at large is slowly changing – an understanding and acceptance of the principles of palliative care is growing;
- Palliative medicine is recognised as a medical subspecialty;
- A new legal framework of health care provision defining palliative care is being developed.

Overall progress in hospice and palliative care:

Hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: Two outpatient palliative care clinics have been established.
- Nursing homes: Formal training of nurses in palliative nursing commenced in 2010, supported by the regional authorities – this has changed the atmosphere in some institutions in relation to the implementation of regular pain assessment.
- Residential homes for the elderly: Some residential homes now offer hospice homecare services.
- Other com. set. No developments.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

The concept of providing palliative care for non-cancer patients is slowly gaining acceptance within the medical community, although no specific services of this type will be developed until 2012.

Perceived barriers to the development of hospice and palliative care:

- Lack of knowledge about specialist palliative care in medical and nursing communities;
- Palliative care is not a priority in the process of healthcare reform which is currently taking place in the Czech Republic;
- Insufficient funding for the design and construction of new palliative care services.

Perceived opportunities for the development of hospice and palliative care:

- Patients and their families are becoming increasingly aware of the possibilities of good palliative care and are beginning to demand it from healthcare providers;
- An increasing number of hospitals are striving for international accreditation (p.e. JCA) – this process raises awareness about different aspects of palliative care;
- A new group of motivated health care providers (physicians and nurses) are becoming increasingly interested in palliative care.

Other issues relevant to the development of hospice and palliative care:

There is no information available at this time.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- The Czech Society for Palliative Medicine (Česká Společnost Paliativní Medicíny ČSL JEP) was formed in 2009; it has a website (www.paliativnimedicina.cz), and is representative of physicians, nurses, social workers and psychologists working in the field of palliative medicine.
- The Association of Providers of Hospice and Palliative Care (Asociace poskytovatelů hospicové paliativní péče), was formed in 2005; it has a website (www.asociacehospicu.cz), and represents the majority of inpatient hospices in the Czech Republic.

Directory or catalogue of palliative care services:

There is an online directory or catalogue of palliative care services (www.umirani.cz); the website provides comprehensive information about (and links to all) inpatient and outpatient hospice and palliative care services in the Czech Republic (the last edition was compiled in 2011).

Congresses, scientific meetings or scientific journals in palliative care:

- There is a palliative care congress: the Czech-Slovak Conference of Palliative Medicine is held annually, attracting approximately 300 participants.
- There are between three and five regional conferences of palliative medicine organised by hospices each year, attended by approximately 50-200 participants.
- The journal *Paliativa Medicina a léčba bolesti* (Palliative medicine and pain management) is published four times per year; it is included in the database *Bibliographia Medica Slovaca* (BMS)
- The journal *Bolest* (Pain) is published six times per year; it mostly examines issues of pain management but some palliative care issues are also addressed. It is included in the EMBASE database.

Palliative care research capacity:

Palliative care researchers include: Ondřej Sláma, Masaryk Memorial Cancer Institut, Brno (oslama@mou.cz); Ladislav Slovák, Department of Oncology and Radiotherapy, Hradec Králové (ladislav.slovacek@seznam.cz); and Marie Macková, Faculty of Nursing, Brno Medical School (mackova@med.muni.cz).

Palliative care collaboration:

- The key pioneer of hospice and palliative care in the Czech Republic since the 1990s has been Dr. Marie Svatošová, a GP who initiated and promoted the idea of hospice care and supported local initiatives which resulted in a 14-bed inpatient hospice being built.
- The Association of Providers of Hospice and Palliative Care have been organising a variety of different events for World Hospice and Palliative Care Day since 2009.

Worldwide palliative care alliance level of development:

4A (Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- Since 2009, palliative medicine has been a part of specialist training for future medical oncologists and GPs and an optional course in three medical schools in the Czech Republic.
- In 2011, palliative care was recognised as a distinct medical subspecialty.
- ELNEC courses were developed in the Czech Republic in 2011.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: - Two medical schools have begun to provide palliative medicine as an optional course; in most medical schools increased importance is now afforded to some aspects of palliative care - pain management, communication, and medical ethics.
- Nursing: Pain management and end-of-life care is part of the curricula in all nursing schools (but the priority given to these issues is relatively low).
- Social work: No developments.
- Other professions: No developments.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: Palliative medicine is recognised as a medical subspecialty; a specific course on palliative medicine is an obligatory part of the specialist training of future general practitioners and medical oncologists.
- Nursing: An accredited course of palliative nursing (based on ELNEC) is offered by two nurse teaching centers.
- Social work: No developments.
- Other professions: No developments.

Translation of palliative care documents or other materials:

The EAPC white paper on standards and norms of hospice and palliative care in Europe was translated and published in the Czech language in 2010.

Initiatives to develop healthcare professional leadership in palliative care:

There is no information available at this time.

Officially recognized medical certification:

- Palliative medicine is officially recognized as a Sub-specialization by the Ministry of Health and the National Institute for Postgraduate Training in Medicine in the following disciplines: clinical oncology, internal medicine, neurology, general family medicine, geriatrics, surgery, pediatrics, and radiation oncology. Rotation in clinical services provides accreditation in education of Palliative Medicine; this involves 20 days of theoretical courses within a twelve-month period. Accreditation commenced in Palliative Medicine and Pain Management (2004), and in Palliative Medicine (2011). Approximately 130 people have achieved accreditation in Palliative Medicine and Pain Management; since 2011, 19 people were trained in Palliative Medicine (to be accredited in 2012).
- There is an accredited specialist course of palliative care for nurses comprising of five days of theory, and five days of practical training; since 2011, approximately 60 nurses have gained accreditation through this course.
- There is also a basic course of palliative nursing (based on ELNEC) – accreditation of this course is “in process”.
- Many hospices organise different courses for nurses and physicians that are accredited within the system of Continuous Medical Education.

Capacity of palliative care workforce training in Universities and Medical Schools:

- In the Czech Republic, there are seven medical schools, none of which provide palliative care as a mandatory component; however, there are two optional courses of palliative medicine as a part of curricula in Brno Medical School and Prague Medical School.
- Some aspects of palliative medicine (pain management, psychological issues, and communication issues) are part of curricula in all medical schools (source: personal experience and expert opinion).

- There are four “other professors of palliative medicine” and 12 “other professors of palliative medicine (non-medical)” in the Czech Republic - ten nurses with some experience and formal training in palliative care and two social workers with some experience and formal training in palliative care (source: personal experience and expert opinion).

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

All WHO essential medications are available in the Czech Republic.

Developments/opportunities/barriers relating to the accessibility of essential medications:

- Regulation of the medical use of both weak and strong opioids is quite “liberal”; every physician is authorised to possess triplicate prescription forms and prescribe all forms of opioids.
- Deep-rooted “opiophobia” among many healthcare professionals is only changing very slowly.

Developments/opportunities/barriers relating to the affordability of essential medications:

The price of some slow-release oral opioids and transdermal opioids is still relatively high (despite being less than half the price they were in 2006); they are more than 90% reimbursed by the National Health Insurance Company. In the inpatient setting (especially in long-term inpatient care with a very limited budget) the high price of opioids may prove to be prohibitive.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to ‘opiophobia’:

Many palliative care education courses for health care providers are organised by various organizations: for example, the Czech Society for Study and Therapy of Pain; Czech Society for Palliative Medicine; Association of the Providers of Hospice and Palliative Care.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

Two new hospices have been built and two palliative care units have been opened in long-term care hospitals. Some residential homes now offer hospice home care services in the Czech Republic

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- In 2008, inpatient hospice care was recognised as a specific type of health care service;
- Specific funding rules relating to palliative care were introduced in 2010 within the new regulation of medical specialities;
- In 2011, palliative care was recognised as a distinct medical Sub-specialty and an Act about Health Care Services (a new legal framework for health care provision in the Czech Republic) was passed that recognised and defined different forms of palliative care provision (inpatient, outpatient and homecare services) as specific forms of health care;
- In 2011, advanced directives were introduced into the Czech healthcare system;
- In 2012, the National Health Insurance Company provided reimbursement for home-based palliative care.

The impact of these policy changes and ways in which they have been important:

There is no information available at this time.

Development of a national palliative care consensus:

In 2011, the National Strategy for Palliative Care in the Czech Republic was debated and prepared by a working group comprising of people from the Ministry of Health, Czech Society for Palliative Medicine, and hospice care providers; a final consensus on the strategy was achieved and the document is currently waiting to be discussed (and accepted) by the Government of the Czech Republic.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

As above.

Development of an advocacy framework for integrating palliative care into the health care system:

There is no information available at this time.

Strategies to improve political awareness and government recognition of palliative care:

There is no information available at this time.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

There is no information available at this time.

Involvement with the European Union in relation to hospice and palliative care initiatives:

There is no information available at this time.

Development of initiatives framing palliative care as a 'human right':

There is no information available at this time.

General legislation relating to palliative care:

As stated, the National Strategy of Development of Palliative Care is being debated by the Czech Government. If passed (hopefully in autumn 2012) it will create a new framework for the development of legislative changes in the field of palliative care.

Published national documents relating to palliative care standards and norms:

- Standards of inpatient hospice care have been available online since 2008 (www.asociacehospicu.cz/)
- Standards of home-based hospice care have been available online since 2006 (last edition updated 2009) www.cestadomu.cz.

National Plan or Strategy of Palliative Care:

As stated, the National Strategy of Development of Palliative Care is being debated by the Czech Government. If passed (hopefully in autumn 2012) it will create a new framework for the development of legislative changes in the field of palliative care.

National Cancer Control Strategy:

The National Cancer Control Programme of the Czech Republic states as one of its specific goals: "to establish a stable network of palliative care departments, hospices and home care services. To establish an evaluation of the quality of life about pain control in patients with advanced cancer".

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy in Czech Republic but it does not contain an explicit reference to palliative care provision.

National Primary Health Care Strategy:

There is no information available at this time.

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

There is no information available at this time.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- Strong opioids are prescribed on specific triplicate prescription forms. Every physician is authorised to possess these prescriptions and to prescribe strong opioids. Strong opioids are available in every pharmacy.
- There are National Guidelines for the Management of Chronic Cancer and Non-Cancer Pain (Doporučené postupy pro léčbu chronické nádorové a nenádorové bolesti) (2009); they are also available online.

Funding of palliative care services:

- Partial payment for palliative care consultation is required although this is mostly covered by public health insurance (the patient may be required to pay 30-50 CZK - 2 EUROS).
- Partial payment for palliative care hospitalisation is required although this is mostly covered by public health insurance (in inpatient hospices patients pay 250 CZK - 10 EUROS).
- Partial payment for palliative care medication is required although this is mostly covered by public health insurance (the maximum payment by a patient for all prescriptions - guaranteed by law - is 3000 CZK/ year - 120 EUROS/year).

The attitude towards hospice and palliative care both within the professional community and in the public at large is slowly changing – an understanding and acceptance of the principles of palliative care is growing

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

There has been a change in public awareness of hospice and palliative care; it is now more widely accepted by both health care professionals and the general public (although there is no data available to support this view).

Major public discussion, debate or controversy about hospice and palliative care:

In 2009-2010, a relatively large discussion about hospice and palliative care took place amongst the medical community and the general public; the discussion also included end-of-life decision making and the process of withholding and withdrawal of life-sustaining therapies. The recommendation of the Czech Medical Chamber is that the physician has the right to decide to either withhold or withdraw therapy if he/she judges it to be futile.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

There is no information available at this time.

Hospice or palliative care 'success' stories:

There is no information available at this time.

Initiatives seeking the legalisation of euthanasia or assisted dying:

Discussion about legislation relating to euthanasia or assisted dying arises in the media and in the public domain on a regular basis. There is no specific movement or initiative striving to achieve such legalisation at the present time.

References

Svecová K. September 2009. "A description and comparison of palliative care services in the United Kingdom and Czech Republic". *Int J Palliat Nurs*; 15(9):422, 424, 426 passim.

Fürst CJ; de Lima L; Prall D; Radbruch L. January 2009. "An update on the Budapest Commitments". *European Journal of Palliative Care*; 16 (1): 22-5.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

Palliative care needs to be developed on two levels: general palliative care (integration of palliative care in the undergraduate and postgraduate curricula of major medical specialities); specialist palliative care (recognition and sustainable funding of outpatient and home-based palliative care services).

Most significant issues facing hospice and palliative care in the next three years:

The process of adoption of the National Strategy of Palliative Care in the Czech Republic and its implementation into the health and social care system; the development of a funding framework of home-based and outpatient palliative care - the Czech Society for Palliative Medicine advocates for these issues.

Implications for palliative care relating to the current economic crisis:

There is a general reluctance to provide better palliative care for patients who are going to die in the foreseeable future. There is also a tendency to misuse palliative care discourse to justify cost-saving measures (leading to a decrease in the availability of qualified medical and nursing care) - this is especially true in long-term care settings.

Palliative medicine is recognised as a medical subspecialty and a new legal framework of health care provision defining palliative care is being developed. Palliative care training for nurses commenced in 2010

Denmark¹

NATIONAL ASSOCIATION

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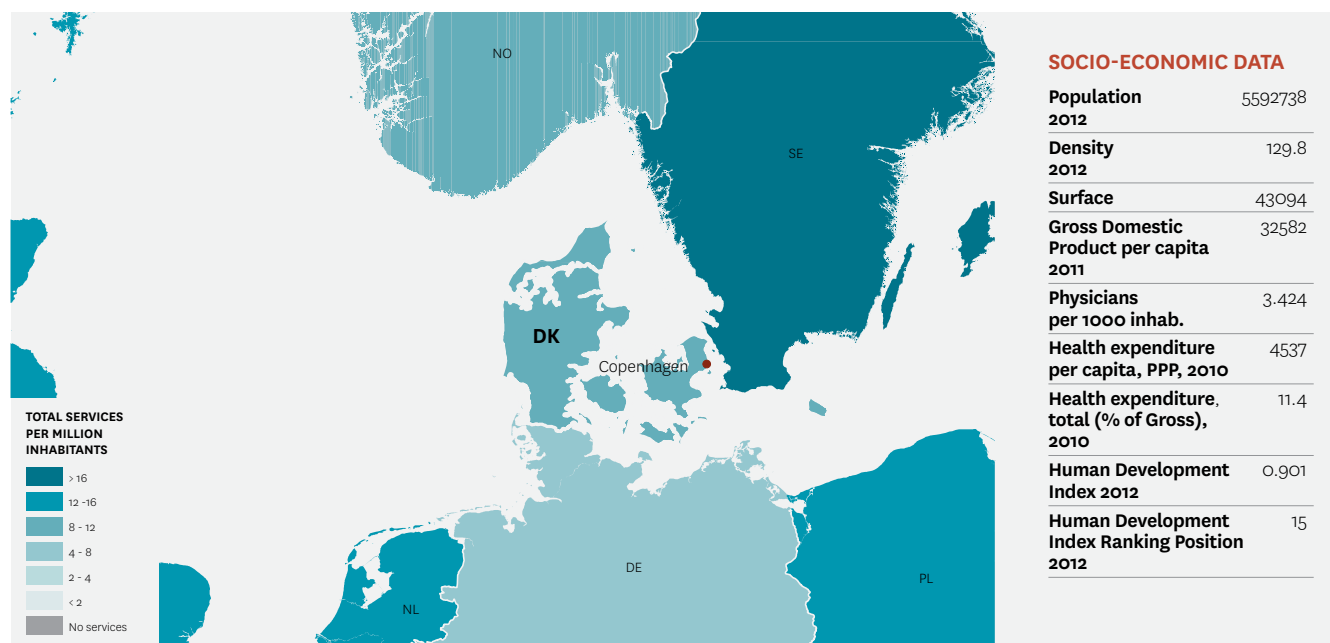
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|--|-----------------------|
| Volunteer hospice team | 28 (220) |
| Hospital palliative care support team | 0 |
| Home palliative care support team | 0 |
| Mixed palliative care support team | 26 (73) |
| Palliative care units in tertiary hospitals | 4 (39) |
| Palliative care units in non-tertiary hospitals | 7 (89) |
| Inpatient hospice | 17 (208) |
| Day hospice/day care centre | 4 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- PAVI's national mapping of specialized palliative care provision in Denmark (2009), and the update of this data every six months since 2009. Palliativt Videncenter (2009): Afrapportering af Palliativt Videncenters kortlægning af det specialiserede palliative niveau i Danmark. Palliativt Videncenter, København. Web: http://www.pavi.dk/Libraries/Nyhedsbrev_marts_2010/Afrapportering_af_Palliativt_Videncenters_kortlaegning_af_det_specialiserede_palliative_niveau_i_Danmark.sflb.aspx.
- Home palliative care team at Diakonissestiftelsens Hospice: <http://www.hospice.diakonissen.dk/Default.aspx?ID=682>
- Home palliative care team at Skt. Lukas Hospice: http://www.sanktlukas.dk/Det_Udgaaende_Hospiceteam-3574.htm
- Home palliative care team at Arresødal Hospice: http://www.arresoedal-hospice.dk/udgaaende_hospiceteam.html
- Personal source: Helle Timm.

- HSE information: bed numbers in in-patient units (hospices) plus one acute hospital in-patient unit are based on information as of February 2012. However, this is subject to change as new health service measures come into force, including budgetary cuts to health spending.

Additional comments:

- The number of volunteer hospice teams comprises of volunteers in hospices (n=17), specialized palliative care teams (n=10) and a specialized palliative care hospital ward (n=1). All Danish volunteer hospice teams and the specialized palliative care hospital ward have a volunteer coordinator; it is unknown if the specialized palliative care teams have co-ordinators (this is currently being investigated). The number of volunteer hospice team beds refers to beds within 17 hospices and one specialized hospital ward.
- All Danish palliative care support teams are defined as "mixed"; 23 of the 26 teams satisfy the criteria of a 'hospital palliative care support team', but as they also provide palliative care at home and supervise and train staff in the municipalities, they are defined as 'mixed palliative care support teams'.
- As of March 2012, there are 26 mixed palliative care support teams in Denmark, but far from all professionals working within these teams are employed on a full-time basis and some of the teams are relatively small. 23 of the teams are based at a hospital, and three of the teams are based at a hospice.
- All of the mixed palliative care support teams comprise of at least one physician with specialist palliative care training (either NSCPM training or accredited training from Cardiff, UK) but not all physicians in the teams have this level of training.
- There are problems with the definitions made in this survey (based on the EAPC White Paper) in relation to the Danish institutions at the specialized level. To some degree, Danish hospices fit the EAPC definition (except for the fact that they don't have many patients "with less complex symptoms"). They are free-standing institutions and about 25% of the patients return to their home or elsewhere after staying in the hospice - and the hospices satisfy the main criteria. However, PAVI is planning to register 'other kinds' of palliative care units and palliative care beds that are now increasingly being defined as "specialized". These could be beds in hospitals or units in the municipalities that also satisfy the main EAPC criteria.

- The number of palliative care units in tertiary hospitals is shown as four but it may be five (or even more). The number of beds includes a minimum of eight outpatient beds.
- In relation to palliative care units in non-tertiary hospitals, there are at least seven such units in Denmark (although there might be more).
- In 2010, the Danish government approved the resources for 42 more hospice beds across five regions of the country; these beds are now being provided in each region in existing hospices (but also potentially in one or two new ones).
- In Denmark there are no hospices or centres entirely dedicated to day care: however, three palliative care units and one palliative care support team provide some form of day care for approximately 12 patients at each location (this number is not yet investigated in a systematic way). One or more additional settings are planning to establish day care centres in 2012 or 2013.

Palliative care services for children:

There is no information available at this time.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

- | | |
|-------------|--|
| 1999 | The National Board of Health publishes guidelines on palliative care in accordance with the WHO definition and with guidelines in the UK. |
| 2004 | The 'Hospice Law' is introduced in Denmark. The government decides that each county should have a hospice, and that the government will fund the building and that each county is obliged to fund the running costs. |
| 2004 | The National Board of Health creates a chapter for the National Cancer Plan II recommending the development of palliative care in Denmark. |
| 2005 | The National Cancer Plan II is published and recommends that palliative care should be offered to all patients with incurable, progressive disease. |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- An escalating growth in the amount of institutions at the specialized level;
- The establishment of nationally coordinated initiatives in the field of palliative care;
- The Danish Knowledge Centre for Palliative Care (PAVI), financed initially by private funds (2009-2011), then financed by the government from 2012. The centre was established by five of the most active organisations in the palliative care field in Denmark. The aim of the centre is to contribute to the development and the diffusion of high quality knowledge about palliative care in Denmark. One very important goal of the organization since 2008 has been to produce an "Atlas" of palliative care in Denmark (please see www.pavi.dk/english);
- The Danish Multidisciplinary Cancer Group for Palliative Care (DMCG-PAL) was formed in 2009; the group has established a Danish Palliative Care Database (DPD). DMCG-PAL is a national framework for coordination and development of palliative care in Denmark and DPD as a research database possesses nine quality indicators for specialist palliative care at 35 specialist care units in the country (please see www.dmcgpal.dk);

- New National Recommendations for Palliative Care in Denmark (National Board of Health, 2011). The recommendations focus on organization and competencies/education. Most significant changes from the former recommendations (1999) are: addressing the needs of non-cancer patients (and not only people suffering from cancer) as described by WHO (2002); the need for palliative care from an early phase (the time of diagnosis), through to the terminal phase; description of the trajectories of rehabilitation and palliation for cancer patients (National Board of Health 2011).
- The most significant contributions to these changes include: the establishment of private hospices since 1992 (a very important "spearhead" in the diffusion of hospice philosophy and palliative care). In 2005, hospices were – by law – made part of the public health care system and this (among other things) is now forcing the public health care system to acknowledge hospices as one of a number of solutions to providing palliative care. After 20 years of working at a local or regional level, some of the key stakeholders began to work on a national agenda; this agenda was supported by politicians, administrators, the mass media and the general public. Funding of palliative care is also significant.
- Since 2007, the cost of specialist palliative care in hospitals (and hospital palliative care support teams) has been obtained through a regional fare system (DRGs). A financial agreement has made it more profitable for general practitioners (private organizations in Denmark) to visit patients at home and to be coordinators to ensure continuity in the palliative care trajectory.
- The Danish Institute for Quality and Accreditation in Healthcare (IKAS) was established in 2005. The initial purpose of the organisation was to develop a joint Danish model for quality in healthcare (<http://www.ikas.dk/English/About-IKAS.aspx>). IKAS plans, develops, and manages the Danish Healthcare Quality Programme (DDKM) which contains five standards concerning palliative care; two at hospitals and three in municipalities.
- The 2007 Municipal Reform changed the distribution of health care responsibilities between the regions and municipalities. Cooperation and coherence are key points in the reform –one important aspect is the development of health agreements with specific focus areas between the regions and municipalities. In the national recommendations (2011) palliative care is proposed as one possible focus area in these health agreements. From 2000 to 2010, Denmark had three national cancer plans: the second (2005) and the third (2010) versions had an increased emphasis on palliative care.

Overall progress in hospice and palliative care:

Hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

In Denmark, palliative care is organized at;

- (a.) a specialized level which is the responsibility of the regions and consists of:
 - Hospices (which are private, but since 2005 have agreements of service with the regions);
 - Mixed palliative care teams (mostly in hospitals and a few in hospices);
 - Palliative care units in tertiary hospitals.
- (b.) a general/basic level, which is the responsibility of either the regions or the municipalities and consists of:
 - General hospital wards and outpatient departments;
 - General Practitioners (who are private, but like other medical specialists have an agreement of service with their region – they work in the communities);
 - Other professionals, who can be employed by the municipality or on a private basis (and have an agreement of service with the municipality), for example, therapists, etc.
 - Home care, nursing care;
 - Nursing homes.
 - Hospitals: In Denmark, a patient is referred to the hospital by the GP or a specialist. Both hospitals and GPs can refer the patient to home care and home care nursing, but it is the municipality that assesses how much care and practical help the patient requires. Within hospitals, there has been a growth in the amount of specialized palliative care provision; less is known about the provision of palliative care at the basic hospital level in general, as it has only recently been investigated for the first time (2011-12/PAVI). However, the PAVI mapping exercise indicates that 20 out of 35 hospital management structures possess a policy for palliative care at their hospital (2011/PAVI).

- Nursing homes: There is limited knowledge about the development of palliative care in nursing homes, although it is known that many Danish nursing homes do pay special attention to palliative care (Karstoft, Nielsen & Timm: Palliativ indsats i den kommunale pleje. 2010/PAVI; Palliativt Videncenter: Kortlægning af den palliative indsats i danske kommuner. 2009/PAVI).

In Denmark, nursing homes are the responsibility of the municipalities and there are three types of home:

- Nursing homes with permanent staff (in 2011, 8,256 elderly people lived in nursing homes which in Denmark are considered as private homes. The estimate of employee workload is based on each person's need for care).
- Nursing homes (private homes for elderly and disabled people) with home care.
- Nursing homes (private homes for elderly and disabled people) with increased accessibility.

A patient must be referred to a nursing home on the basis of care needs - and regardless of personal finance.

- Residential homes for the elderly: In Denmark, there are no specific residential homes for the elderly but rather different types of nursing homes/homes for the elderly.
- Other community settings: In Denmark the core of the primary health care system consists of the GP, home care nurses and other support staff.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

There has been a focus on cancer patients to address the needs of 'non-cancer' patients, but only recently. Firstly, the new national recommendations on palliative care (2011) stress that palliative care is for all patients and relatives suffering from a life-threatening disease (not only from cancer) and their relatives. Secondly, there has been progress in research with a focus on palliative care for people living with, for example, heart failure.

Perceived barriers to the development of hospice and palliative care:

(i) The economy. In 2010, the Finance Act recommended an expansion of the Danish specialized palliative care system - primarily 42 new hospice beds. Despite both regions and municipalities having many obligations, the Finance Act provided no economic support for the proposed expansion or strengthening of palliative care; (ii) Another barrier is the competency of professionals, many of whom do not possess the relevant competences to provide high-quality palliative care at either the basic or at the specialized level. It is difficult to recruit the required amount of doctors that are needed at the specialized level; the basic level of palliative care is characterized by fewer nurses and more assistants (with less education); (iii) A third barrier is the terminology and definitions within the health care system relating to palliative care and the practical division of work required to provide it. In Denmark, discussion has only recently commenced about providing palliative care from the very start of the disease trajectory, about determining palliative care needs and about the relationship between rehabilitation and palliation. To promote the understanding of these concepts, better terminology and clearer definitions of palliative care are required.

Perceived opportunities for the development of hospice and palliative care:

(i) The new national recommendations (2011) represent an updated political and professional approach to palliative care which will hopefully prove to be innovative within the Danish health care system (both the political and the professional part of it) and thereby continue the development of the palliative care field in Denmark (ii) The systematic documentation of palliative care - through, for example, PAVI's national mapping, The Danish Database of Palliative Care/DMCG-PAL and increased research in general - provides a better overview of where palliative care can be improved; this may serve to strengthen international cooperation and promote international comparison and collaboration; (iii) A growing awareness and interest among the general population and mass media that places palliative care on a broader societal agenda (e.g. within the standards, goals, priorities and financing of the welfare state) and issues surrounding life and death in Denmark.

The cost of palliative care in hospitals (and hospital palliative care support teams) is now obtained through a regional fare system making it more profitable for general practitioners to provide palliative care at home

Other issues relevant to the development of hospice and palliative care:

- NGOs providing palliative care are of great importance to the development of the discipline in Denmark. Many of the NGOs are professional and some of the most important since 2006 include: Dansk Selskab for Palliativ Medicin (The Danish Society for Palliative Medicine); Foreningen for Palliativ Indsats - omsorg ved livets afslutning (The Association for Palliative Care); Gruppen af Ledere ved Hospice, Palliative Teams og Palliative Enheder (The Group of Leaders in Hospices, Palliative Teams and Palliative Units); Hospice Forum Danmark (The Danish Hospice Forum); and Kræftens Bekæmpelse (The Danish Cancer Society). In 2006, a national interdisciplinary network of researchers undertaking palliative care research was established. The network is coordinated by a member of the Danish Society for Palliative Medicine, and has approximately 95-100 members (as of November 2011); there is an annual meeting which is arranged by various members of the network (www.palliativ-medicin.dk).
- Professionals such as psychologists, social workers and physical therapists working in palliative care have formed their own national associations in palliative care based on their profession.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- The Association for Palliative Care (Foreningen for Palliativ Indsats) was formed in 1990; it has a website (www.palliativ.dk/), and is representative of the whole country.
- The Danish Multidisciplinary Cancer Group for Palliative Care (Dansk Multidisciplinær Cancer Gruppe for Palliativ Indsats (DMCG-PAL) was formed in 2009; it has a website (<http://www.dmcgpal.dk/>), and is representative of the whole country. The organization (established by the National Board of Health) has developed a National Clinical Database for Specialised Palliative Care.
- There are many more other professional groups interested in palliative care in Denmark.

Directory or catalogue of palliative care services:

There is an online catalogue of palliative care services - Palliativguiden (<http://pavi.dk/Palliativguiden.aspx>): the first edition went online in 2010 (the latest edition, March 2011). Palliativguiden contains details of specialist palliative care services provided by the Danish Knowledge Centre for Palliative Care (PAVI). PAVI is planning to expand the information in the Palliativguiden and present non-specialist palliative care services as inpatient beds in nursing homes (by June 2012) and inpatient beds at non-specialist hospital wards with a special focus on palliative care (by 2013).

Congresses, scientific meetings or scientific journals in palliative care:

- Palliation i Danmark - (current status and vision) was a one-off national congress held in 2010 and attended by approximately 120 participants;
- Kommunal palliativ indsats (Palliative care in the municipalities) was a one-off national congress held in 2010 and attended by approximately 170 participants;
- Palliativ indsats på danske sygehuse - status og visioner (Palliative care in Danish hospitals - current status and visions) was a one-off national congress held in 2012 (unknown number of participants);
- Forskningsnetværk i palliation (Palliative research network) is a national congress held annually since 2009 and attended by approximately 30 participants;
- The International Seminar of the PRC and EAPC is a national congress held annually since 2011 and attended by approximately 175 participants;
- Palliativ indsats til mennesker med demens (Palliative care for people diagnosed with dementia) was a one-off national congress held in 2012 and attended by approximately 125 participants;
- Årsmøde i Dansk Multidisciplinær Cancer Gruppe for Palliativ Indsats (Annual meeting of the Danish Multidisciplinary Cancer Group for Palliative Care), is a national congress held annually since 2011 and attended by approximately 180 participants;

- Foreningen for Palliativ Indsats – omsorg ved livets afslutning (The Association for Palliative Care) is a national congress held bi-annually since 2001 and attended by approximately 180 participants.
- Dansk Selskab for Palliativ Medicin (DSPaM: The Danish Society for Palliative Medicine) hold an annual meeting.
- Attended by approximately 30 participants each year.
- The Danish Association for Psychologists in Palliative care, Physical Therapists in Palliative Care and Social Workers in Palliative Care have annual meetings attended by approximately 30 participants from each profession.
- Danish professionals in palliative care are very active as editors of the Nordic palliative journal "Omsorg" (Care. Nordic Journal of Palliative Care) which is published four times per year.

Palliative care research capacity:

- Palliativ Medicinsk Afdeling P, Bispebjerg Hospital (Research Unit, Department of Palliative Medicine, Bispebjerg Hospital), Bispebjerg Bakke 23, 2400 Copenhagen NV, Denmark. Phone: +45 35 31 62 25, e-mail: palliative@bbh.regionh.dk;
- Palliativt Videncenter (Danish Knowledge Centre for Palliative Care), Strandboulevarden 47B, 1th floor, 2300 Copenhagen S, Denmark. Phone +45 30 38 23 02, e-mail: pavi@pavi.dk
- Humanistisk Palliation, Institut for Organisation og Sociale Forhold, Ålborg Universitet (Humanistic Palliation Master Program, Institute for Sociology and Social Work, Aalborg University), Michael Hviid Jacobsen, Professor of Sociology and Director of Master Courses in Humanistic Palliation, Institut for Sociologi og Socialt Arbejde, Kroghstræde 5, Lokale 11, 9220 Aalborg Ø. Phone: +45 99 40 81 20. E-mail: mhj@socsci.aau;
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- Smerteklinikken Rigshospitalet (Acute Pain Treatment Unit, Copenhagen Hospital), Per Sjøgren. Consultant, (Enhed for Akut Smertebehandling, Rigshospitalet). Address: Section 4114, Rigshospitalet, Copenhagen University, DK-2100 Copenhagen. Phone: +45 35 45 71 24. E-mail:
- Forskningsnetværket i palliation (The Research Network, The Danish Society for Palliative Medicine) currently has 96 individual members (not all researchers): Mette Asbjørn Neergaard. Consultant, Coordinator of the Research Network, (Forskningsnetværket, Dansk Selskab for Palliativ Medicin). Address: Fællessekretariatet, Trondhjemsvej 9, 2100 København Ø Phone: +45 35 44 84 03. E-mail: man@alm.au.dk.

Palliative care collaboration:

- In Denmark, palliative care teams and palliative care wards cooperate with hospices; physicians in these teams and wards usually see patients at local hospices. The specialized palliative care teams also cooperate with non-specialized hospital wards in relation to palliative care education and training.
- The Danish Association for Palliative Medicine (DSPaM) is a member of the EAPC and a part of the group that provides the Nordic Specialist Course in Palliative Medicine (NSCPM). Dr. Per Sjøgren is a board member of the DSPaM, and vice-president of the EAPC. Several members of DSPaM are in EAPC working groups or on Task Forces; for example, Denmark is represented on the EAPC task force for developing a curriculum for psychologists working in palliative care (Mai-Britt Guldin). Tove Vejlgård is chairman of the steering group of the NSCPM; Bodil Jespersen and Lise Pedersen are responsible for developing 1.5 modules of the course.
- Pioneers include Sankt Lukas Hospice (the first hospice in Denmark, created in 1992); Dansk Selskab for Palliativ Medicin (The Danish Society for Palliative Medicine); Foreningen for Palliativ Indsats – omsorg ved livets afslutning (The Association for Palliative Care) – a multi-professional organisation created in 1995; Gruppen af Ledere ved Hospice, Palliative Teams og Palliative enheder (The Group of Hospice Leaders, Palliative Teams and Palliative Units); Hospice Forum Danmark (The Danish Hospice Forum) and Kræftens Bekæmpelse (The Danish Cancer Society). The Danish Association for Palliative Medicine was created in 2001. Hospice Forum Denmark was established in 2001 (A non-professional organisation aiming to develop hospice care in Denmark). A task force group consisting of managers from hospice and palliative care organizations have collaborated closely in recent years. The National Board of Health has also actively supported the development of palliative care in Denmark.

- Hospice Forum Danmark (The Danish Hospice Forum) promotes World Hospice and Palliative Care Day in Denmark (in Danish it is called International Hospicedag). On World Hospice and Palliative Care Day 2012, the Danish Hospice Forum celebrated 20 years since the establishment of the first hospice in Denmark (Sankt Lukas Hospice); other hospices in Denmark celebrated the day with speeches, concerts and exhibitions.

Worldwide palliative care alliance level of development:

4A (Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- Hundreds of healthcare professionals (mainly nurses) working at the basic level in hospitals and (mainly) in the communities have been educated in palliative care. A Diploma in Cancer Nursing, specifically addressing palliative care (<http://www.phmetropol.dk/Videreuddannelser/Efteruddannelser/Specialuddannelsen-ii-kraeftsygepleje>) is available at one of the University Colleges (Metropol);
- Since 2004/2005, the Ministry of Education has offered free vocational training in palliative care for social and health care assistants and helpers;
- Since 2009, the Basic Health Care Colleges have provided a flexible national programme 'Kompetenceudvikling for Social- og sundheds Assisterter' (KUA) [Competence Development for Social and Healthcare assistants] consisting of palliative care modules;
- Most hospices, palliative care units and teams organize continuing education – either as specific education or when needed upon request. Content of this education includes symptom relief, spiritual care, grief and loss, caring for relatives, ethics, social palliation, communications and inter-sectoral collaboration;
- Since 2010, the Danish Multidisciplinary Cancer Group for Palliative Care (DMCG-PAL) has described the required educational needs of all relevant professions in palliative care. The project has resulted in the development of a curriculum for all palliative care professionals (scheduled for completion in 2012).

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Palliative care in the under-graduate system has not developed much; the discipline is not part of medical curricula at this level and it is left to individual schools to decide if it should be included. The new national recommendations (2011) suggest that relevant Bachelor Degree Programmes prepare curricula about palliative care before the end of 2013. Currently, DMCG-PAL describes the competencies to be achieved at the various educational levels – including at the level of Bachelor Degree.
- Nursing: To date, the competency required for the Bachelor Degree in Nursing has been completed, and will be implemented in cooperation with the University Colleges.
- Social work: No developments.
- Other professions: No developments.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: Since 2003, Danish doctors can undertake the Nordic Specialist Course in Palliative Medicine. The course is a joint venture between the Associations of Palliative Medicine in the five Nordic countries and comprises of a theoretical specialist training course consisting of six modules over the course of two years. The course is developed for physicians who have been trained as specialists in relevant clinical specialties and require expertise in palliative medicine at a specialist level. (<http://www.nscpm.org/>).

- **Nursing:** Since 2004, it has been possible for professionals with a Bachelor Degree (nurses, physiotherapists, occupational therapists and social workers) to obtain a Diploma in Palliative Care. From 2011, this program offers three modules in palliative care and currently, four of Denmark's seven University Colleges offers these modules. Since 2010, Aalborg University has offered an interdisciplinary Master's Program in 'Human Palliation' for professionals involved in care related to end-of-life (<http://www.mhp.aau.dk/>). The Program consists of four modules and offers the possibility for students to select either all or some of the modules. The Program is directed at both multidisciplinary and inter-sectoral professions that work within nursing/caring services. The Program aims at providing theoretical insight and practical experience within several areas (e.g. palliation, gerontology, sociology, psychology, ethics/philosophy/theology, etc.)
- **Social work:** As above.
- **Other professions:** As above.

Translation of palliative care documents or other materials:

The EORTC-QLQ-C15-PAL (2006) and the Edmonton Symptom Assessment System (ESAS) (2009) have been translated into Danish.

Initiatives to develop healthcare professional leadership in palliative care:

There have been some individual initiatives to develop healthcare professional leadership in palliative care.

Officially recognized medical certification:

- Almost all physicians working in Danish specialized palliative care institutions have a relevant medical specialization – e.g. oncology, internal medicine and anesthesiology. Palliative Medicine is not a medical specialty in Denmark, and there is no official accreditation process to date. Palliative Medicine is not a subspecialty either, but rather a 'field of competence'. The Danish Association for Palliative Medicine (DSPaM) is currently working on this issue; the aim is to have this 'field of competence' recognised within the National Board of Health, and to have a procedure developed for accreditation by 2013.
- Other forms of accreditation include the Nordic Specialist Course in Palliative Medicine (NSCPM); to date 30 Danish doctors have completed the NSCPM, and a further 11 are currently undertaking the course. In addition to the NSCPM, approximately ten doctors have obtained the Diploma in Palliative Medicine from Cardiff University, and one has obtained the MSc in Palliative Care from King's College, London. These courses/degrees satisfy the criteria required relating to the theoretical part of specialist training.

Capacity of palliative care workforce training in Universities and Medical Schools:

- Denmark has four medical schools (source: personal experience). The National Recommendations for Palliative Care in Denmark (National Board of Health, 2011) suggest that all relevant Bachelor Degree Programmes prepare curricula containing palliative care before the end of 2013.
- There are one/two full professors in palliative medicine; the first academic chair in Palliative Medicine was established in Denmark in 2011 (Per Sjøgren, University of Copenhagen). In 2012, a professor in 'Palliative care and quality of life research' will be established at the University of Copenhagen. Several assistant professors may undertake research or have an interest in palliative medicine, but there are no other chairs officially dedicated to palliative medicine.
- Palliative care is taught at Bachelor Degree level in nursing, physiotherapy and social work and partially at Bachelor Degree level in therapy, psychology and theology (Source: Meldgaard A, Henriksen J, Madsen KH. Kortlægning af formelle kvalifikationer og uddannelse i palliativ indsats på grunduddannelsesniveau i syv uddannelser: Sygeplejerske, fysioterapeut, ergoterapeut, socialrådgiver, medicin, psykologi og teologi. Viola - Videncenter for Omsorg, Liv og Aldring, 2010).

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- According to the International Narcotics Control Board (INCB), Denmark has one of the highest levels of legal use of strong opioids per capita in the world - so the availability/accessibility of opioids is high.
- The prescribing of weak opioids (codeine and tramadol) follow the same rules as the prescribing of ordinary medication, but the prescribing of strong opioids must fulfil certain criteria. However, it is very easy for all medical doctors to prescribe strong opioids. The doctor has to provide his/her unique CPR-number (Central Personal Registration- number) when prescribing strong opioids, and the pharmacy sends a copy of the prescription to the Danish Medicines Agency (DMA), where the copy is archived. However, the ease of prescribing opioids does not necessarily equate with a high quality of pain treatment. On the level of the cancer/palliative care population, comprehensive knowledge about the quality of pain treatment is still lacking.
- In Denmark, general practitioners can write a "terminal declaration" that provides the right to free medical and other social healthcare services, such as the right of a family member to take paid passionate leave;
- In 2007, the palliative care team (from the city of Vejle) developed a "safety box" containing the pain-relieving medications that are generally needed to relieve the pain of cancer patients. The safety box may be prescribed by general practitioners to patients who receive care at home and can be used when needed - usually in cooperation with general practitioners, home care nurses and a specialized palliative care team (<http://www.sygehuslillebaelt.dk/wm262388/> <http://www.sygehuslillebaelt.dk/wm261893/>).

Developments/opportunities/barriers relating to the accessibility of essential medications:

Essential medications are provided mostly for cancer patients that have received a terminal prognosis; pharmaco-epidemiological studies have shown that almost 75% of this group of patients receive opioids sometime during the last three months of life. This frequency is in accordance with the findings that around 70-90% of patients with advanced cancer experience pain (Jarlbaek L, Hansen DG, Bruera E, Andersen M. Frequency of opioid use in a population of cancer patients during the trajectory of the disease. Clin Oncol (R Coll Radiol). 2010 Apr; 22(3):199-207.)

Developments/opportunities/barriers relating to the affordability of essential medications:

There is no information available at this time.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

There is no information available at this time.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

The National Cancer Plan (2010) has an increased emphasis on palliative care and the Danish Knowledge Centre for Palliative Care has been funded by the Government from 2012 (previously it was privately funded)

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

The 2007 Municipal Reform – health agreements with a possible focus on palliative care; the third Cancer Plan (2010) – this plan increases the focus on palliative care; the 2010 and 2011 Financial Acts – provision of 42 new hospice beds.

The impact of these policy changes and ways in which they have been important:

- More specialized palliative care institutions have been developed;
- Improved palliative care at the basic level (in the last 14 years, more than a thousand people have been taught by specialized palliative care staff to work as “key persons” at the basic level) (Source: Marianne Pedersen (2011): Kortlægning af danske nøglepersonersuddannelser i palliation. Copenhagen, Palliativt Videncenter);
- More initiatives in regions and municipalities such as: plans and strategies for palliative care/cooperation between specialized and basic palliative care institutions/regional cooperation models – e.g. the SAM-BO agreement between hospitals, municipalities and general practitioners in Southern Denmark which states that hospitals, municipalities and general practitioners must enter into dialogue as soon as palliative care patients are admitted in order to ensure continuity in patient care (<http://www.regionsyddanmark.dk/wm258038>);
- A growing awareness and interest about palliative care among the general population, healthcare professionals and the mass media has placed the discipline on a broader societal agenda.

Development of a national palliative care consensus:

- Nye nationale anbefalinger for palliativ indsats (New National Recommendations for Palliative Care in Denmark. National Board of Health, 2011). http://www.sst.dk/publ/Publ2011/SYB/Palliation/PalliativeIndsats_anbef.pdf;
- Forløbsbeskrivelse vedr. Rehabilitering og palliation for kræftsyge (Pathways concerning rehabilitation and palliation in cancer care. <http://www.sst.dk/publ/Publ2012/SYB/Kraeft/RehabPalliationForloebprog.pdf> (National Board of Health, 2012);
- Den Danske Kvalitetsmodel (DDKM) (The Danish Quality Model) includes national standards for palliative care in hospitals and in municipalities <http://www.ikas.dk>.
- In December 2010, the Danish National Board of Health published Kræftplan III (National Cancer Plan III). This third edition emphasizes palliative care (<http://www.sum.dk/Aktuelt/Nyheder/Kraeft/2010/November/~media/Filer%20-%20dokumenter/KraeftplanIII/Aftaletekst-kræftplan-III.ashx>);
- Danish Health legislation regulates some areas of palliative care (for more details see Sundhedsloven LBK. Nr. 913 af 13.07.2010: <https://www.retsinformation.dk/forms/ro710.aspx?id=130455> and Lov om Social Service LBK. Nr. 904 af 18.08.2011: <https://www.retsinformation.dk/forms/ro710.aspx?id=136390>).

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

- Many national meetings have taken place in connection with the above mentioned initiatives: to implement the new national recommendations, a working group of more than 25 experts, stakeholders and policy makers was established – with a reference group consisting of the same number of people; to establish the Danish Knowledge Centre for Palliative Care, the Danish Multidisciplinary Cancer Group for Palliative Care, The Danish Palliative Care Database and other assorted initiatives, there were many more such meetings;
- The Danish Knowledge Centre for Palliative Care has been the host of national conferences addressing palliative care strategies: in February 2010, the focus of the first conference was “Status and development of palliative care in Denmark”; in October 2011, the focus of the second conference was “Status and development of palliative care in the Danish Municipalities”; in November the focus of the third conference was “Status and development of palliative care in Danish hospitals”.

Development of an advocacy framework for integrating palliative care into the health care system:

There have been some “local” advocacy frameworks for integrating palliative care into the health care system, e.g. the Danish Cancer Society has a framework announcing palliative care for cancer patients.

Strategies to improve political awareness and government recognition of palliative care:

There have been many different strategies to improve political awareness and government recognition of palliative care – among the different NGOs, public authorities, etc. – but as a more common strategy, in 2009 the cooperation between five Danish palliative care organizations resulted in the first Danish Knowledge Centre for Palliative Care (PAVI). The five organizations are: Dansk Selskab for Palliativ Medicin (The Danish Society for Palliative Medicine); Foreningen for Palliativ Indsats – omsorg ved livets afslutning (The Association for Palliative Care); Gruppen af Ledere ved Hospice, Palliative Teams og Palliative Enheder (The Group of Leaders at Hospices, Palliative Teams and Palliative Units); Hospice Forum Danmark (The Danish Hospice Forum); Kræftens Bekæmpelse (The Danish Cancer Society). The DMCG-PAL is also the result of such a strategy; this initiative resulted from the Danish Society for Palliative Medicine and the structure of the DMCGs is based predominantly in the regions.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

Some private funding of palliative care research, development (and to a smaller extent practical issues) has taken place in Denmark by funders such as TrygFonden and the Danish Cancer Society (but others as well). From 2009–2011, the Danish Knowledge Centre for Palliative Care was mainly funded by TrygFonden, the Danish Cancer Society and some other private funders; from 2012, the centre is mainly funded by the Danish government. EAPC-PAL is funded by the regions – but work-force capacity is supported by specialized institutions, PAVI and other funders.

Involvement with the European Union in relation to hospice and palliative care initiatives:

On Monday 26th March 2012, there will be a hearing in the European Parliament and a Danish representative (Mogens Grønvald) will describe the work of DMCG-PAL in Denmark.

The Danish Multidisciplinary Cancer Group for Palliative Care has established a Danish Palliative Care Database, and National Recommendations for Palliative Care in Denmark were produced by the National Board of Health in 2011

Development of initiatives framing palliative care as a 'human right':

- There has not been much development of initiatives framing palliative care as a 'human right'. Unfortunately, the new national recommendations for palliative care (The National Board of Health, 2011) do not have a special chapter relating to the rights of Danish citizens (although they will improve patients' rights to an extent).
- In 2012, the Danish Knowledge Centre for Palliative Care (PAVI) launches web pages (www.pavi.dk) specially targeting Danish citizens (until now the website has been a platform for palliative care professionals only).
- In 2010, the Danish Council of Ethics discussed whether the recommendation to the Government to ban euthanasia should be maintained; the discussion was based on the theme of human rights. The council was not unanimous but the majority supported the current recommendation (<http://etiskraad.dk/Nyhedsarkiv/2010/marts/Debat-om-eutanasi-og-palliativ-behandling.aspx>).

General legislation relating to palliative care:

Sundhedsloven LBK. Nr. 913 af 13.07.2010: [https://www.retsinformation.dk/forms/ro710.aspx?id=136390/Care fees - Lov om Social Service § 119, § 120 og § 121/Financial support to nursing articles - Lov om Social Service § 122/Covering additional expenses due to dependence of seriously ill children - Lov om Social Service § 41/Earnings replacement to parents with seriously and terminally ill children - Lov om Social Service § 42](https://www.retsinformation.dk/forms/ro710.aspx?id=130455/Treatment of terminally ill person - Sundhedsloven § 25 /Will - Sundhedsloven § 26/Disclosure of information concerning deceased patients illness, cause of death and manner of death - Sundhedsloven § 45/Legislation concerning hospice - Sundhedsloven § 75, 79 stk. 2 and § 86/Reimbursement and drugs - Sundhedsloven § 148/Reimbursement and nutrition preparations - Sundhedsloven § 159/Transport compensation - Sundhedsloven §170- § 173/Inquest - Sundhedsloven § 176/Social legislation - Law on Social Services (LBK. Nr. 904 af 18.08.2011): <a href=).

Published national documents relating to palliative care standards and norms:

- (Printed standards): Anbefalinger for den palliative indsats (Recommendations for palliative care) published in 2011 - replaced earlier recommendations from 1999;
- (Printed standards): Forløbsbeskrivelse vedr. Rehabilitering og palliation for kræftsyge (Pathways concerning rehabilitation and palliation in cancer care) published in 2012 (first version 2005);
- (Printed standards): Den Danske Kvalitetsmodel (DDKM) (The Danish Quality Model), includes national standards for palliative care at hospitals and in municipalities (since 2005);
- (Online standards): Anbefalinger for den palliative indsats (Sundhedsstyrelsen 2011): http://www.sst.dk/publ/Publ2011/SYB/Palliation/PalliativeIndsats_anbef.pdf / Forløbsbeskrivelse vedr. rehabilitering og palliation for kræftsyge/)
- (<http://www.sst.dk/publ/Publ2012/SYB/Kraeft/RehabPalliationForloebprog.pdf> Den Danske Kvalitetsmodel (DDKM) (2012) (www.ikas.dk).

National Plan or Strategy of Palliative Care:

- In December 2012, the Danish National Board of Health published new national recommendations for palliative care "Anbefalinger for den palliative indsats" (Recommendation for palliative care):
- Online publication: http://www.sst.dk/publ/Publ2011/SYB/Palliation/PalliativeIndsats_anbef.pdf.
- In 2012, the Danish National Board of Health also published a description of pathways concerning rehabilitation and palliation in cancer care "Forløbsprogram for rehabilitering og palliation i forbindelse med kræft":
- Online publication: <http://www.sst.dk/publ/Publ2012/SYB/Kraeft/RehabPalliationForloebprog.pdf>.

National Cancer Control Strategy:

In December 2010, the Danish National Board of Health published Kræftplan III (National Cancer Plan III). (<http://www.sum.dk/Aktuelt/Nyheder/Kraeft/2010/November/~media/Filer%20%20dokumenter/KraeftplanIII/Aftaletekst-kræftplan-III.ashx>).

National HIV/AIDS Strategy:

There is no National HIV/AIDS Strategy in Denmark.

National Primary Health Care Strategy:

The Danish Association of General Practitioners (Dansk Selskab for Almen Medicin) has published the clinical guideline "Palliation i primærsektor" (Palliation in the primary health care sector); it contains explicit reference to palliative care provision (<http://www.e-pages.dk/dsam/172074491/>). The clinical guideline is to be revised in 2012.

Designated policy maker for the delivery of palliative care services:

There is no designated policy maker for the delivery of palliative care services. The Finance Act of 2010 dictates that from 2011 onwards, two million Danish kroner will be allocated annually to strengthen monitoring and quality in the area of cancer, including the use of clinical quality databases in national monitoring of the disease (under the auspices of DMCG). The National Board of Health has published guidelines relating to palliative care; the most recent version is from December 2011 (http://www.sst.dk/publ/Publ2011/SYB/Palliation/PalliativeIndsats_anbef.pdf).

Department of Health specific responsibility for the delivery of palliative care services:

The responsibility for the delivery of palliative care services is placed with representatives within the five regions (hospitals, hospices and GPs) and the 98 municipalities (own homes and nursing homes). However, the Ministry of Health has responsibility for national plans and recommendations, as well as for parts of the national economy that relates to the health care system and has annual budgets that have to be mutually agreed upon by members of the government.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

The Danish Healthcare Quality Program is a system of internationally recognized accreditation that has standards concerning palliative care (regarding the palliative care approach, not specialist palliative care). The mappings made by PAVI serve as (among other things) a mapping or evaluation of the current status of palliative care at the structural level. The Danish Database of Palliative Care/DMCG-PAL (Den Nationale Palliative Database) is another initiative aimed at measuring standards of specialized palliative care across the country.

Opioid legislation/Pain guidelines:

- When prescribing opioids, the physician needs to provide more personal data than for other forms of prescription.
- Pain guidelines are in process; DMCG-PAL is in the process of creating an evidence-based guideline for the management of pain in cancer patients (expected 2012).

Funding of palliative care services:

- There are no payments required for palliative care consultation or hospitalisation.
- Partial payments are required for palliative care medications.
- External funders of palliative care research include: the Danish Cancer Society; TrygFonden Foundation; EGV; A.P. Møller. Many Danish palliative care research and development projects are funded by universities and private funds.

Progress includes the 2007 Municipal Reform – health agreements with a possible focus on palliative care; the third Cancer Plan (2010) – this plan increases the focus on palliative care; the 2010 and 2011 Financial Acts – provision of 42 new hospice beds

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

PAVI is conducting a survey amongst the Danish population in 2012 to investigate levels of knowledge and awareness of death, dying and palliative care (this kind of survey has not been conducted before).

Major public discussion, debate or controversy about hospice and palliative care:

There has not been major public discussion, but occasionally the media highlights stories about patients or relatives who do not receive sufficient end-of-life or palliative care (most stories concern hospitals and nursing homes).

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

- The Danish Knowledge Centre for Palliative Care (PAVI) seeks to broaden awareness and understanding of hospice and palliative care - especially through a project that is being undertaken in 2012: The Danes – knowledge and wishes about death and dying;
- In 2011, PAVI was reported in the mass media on approximately 40 occasions.

Hospice or palliative care ‘success’ stories:

- The 17 hospices in Denmark generally receive very positive publicity and they have certainly helped to promote efforts to care for sick and dying people and their relatives in the country. Hospices are usually founded by local support associations, and recruit a large number of volunteers (by Danish standards).
- In 2011, the Danish national television channel (DR1) featured a documentary - *Sømanden og juristen: historier fra et hospice* (The sailor and the lawyer: stories from a hospice). The journalist who made the documentary, Anders Agger, received a national prize for the documentary (http://www.dr.dk/DR1/Dokumentar/2011/Soemanden_Juristen_-_historier_fra_et_hospice/20110415130928.htm#/10324) (<http://www.livogdoed.dk/Presse.aspx?ID=831&Action=1&NewsId=246&M=NewsV2&PID=4124>).

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is an association ("Landsforeningen En værdig død" [The National Association - A Dignified Death]) and a number of individuals who argue for the introduction of euthanasia in Denmark. The question is regularly raised in the media (once or twice a year), where the lack of legalization is often contrasted with opinion polls showing that a large proportion of Danes are in favour of euthanasia. The Danish Council of Ethics plans to resume the debate.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

Within the next five years, Denmark may see: a larger regional regulation of specialized palliative care so that different kind of organizations (hospices, palliative care teams and hospital units) complement each other in an intensified division of labour - as well as developing new types of palliative care services, such as day care centers; a greater focus on and development of basic palliative care services in both municipalities and at hospitals - as well as a development of new types of services, such as municipal hospices and palliative care beds at oncology or internal medicine wards; a greater focus on efforts aimed at a wide range of groups with palliative care needs (especially heart disease, lung disease and dementia patients). Also, within the framework of DMCG-PAL national clinical guidelines are being developed for the most common symptoms in palliative care in Denmark.

Most significant issues facing hospice and palliative care in the next three years:

A focus on the ability to define how palliative care efforts should be organized - what is specialized and what is basic palliative care, what the areas of research should be and who should conduct the research; PAVI and DMCG-PAL will play an important role in addressing these issues.

Implications for palliative care relating to the current economic crisis:

It may be more difficult to refer patients to specialized palliative care services and the development of basic palliative care services may be based on funds available during the economic crisis (and the limited number of adequately trained personnel).

The 17 hospices in Denmark generally receive very positive publicity and they have certainly helped to promote efforts to care for sick and dying people and their relatives in the country. Hospices are usually founded by local support associations, and recruit a large number of volunteers

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | ○ |
| Hospital palliative care support team | ○ |
| Home palliative care support team | 15 |
| Mixed palliative care support team | ○ |
| Palliative care units in tertiary hospitals | ○ |
| Palliative care units in non-tertiary hospitals | ○ |
| Inpatient hospice | ○ |
| Day hospice/day care centre | ○ |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

Personal estimates/estimates provided by experts.

Additional comments:

There are no organized palliative care services in Estonia.

Palliative care services for children:

There are no organized paediatric palliative care services in Estonia.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

There have been no palliative care milestones in Estonia.
EAPC Palliative Care Euro-Barometer 2005.

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

There have been no significant changes in hospice and palliative care in Estonia.

Overall progress in hospice and palliative care:

Hospice and palliative care has remained the same.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: Palliative care is not organised, but it is mostly hospital-based.
- Nursing homes: There is no information available at this time.
- Residential homes for the elderly: There is no information available at this time.
- Other community settings: There is no information available at this time.

Expansion from a focus on cancer patients to address the needs of ‘non-cancer’ patients:

There is no information available at this time.

Perceived barriers to the development of hospice and palliative care:

(i) Lack of finances (ii) lack of interest amongst people.

Perceived opportunities for the development of hospice and palliative care:

(i) Providing care to patients.

Other issues relevant to the development of hospice and palliative care:

There is no information available at this time.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

There is no information available at this time.

Directory or catalogue of palliative care services:

There is no information available at this time.

Congresses, scientific meetings or scientific journals in palliative care:

There is no information available at this time.

Palliative care research capacity:

There is no information available at this time.

Palliative care collaboration:

There is no information available at this time.

Worldwide palliative care alliance level of development:

Group 2 (capacity-building activity).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

There are some palliative care education and training initiatives in Estonia.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: There are some palliative care lectures.
- Nursing: There are some palliative care lectures.
- Social work: There are some palliative care lectures.
- Other professions: There are some palliative care lectures.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: There are some palliative care lectures.
- Nursing: There are some palliative care lectures.
- Social work: There are some palliative care lectures.
- Other professions: There is no information available at this time.

Translation of palliative care documents or other materials:

There is no information available at this time.

Initiatives to develop healthcare professional leadership in palliative care:

There is no information available at this time.

Officially recognized medical certification:

There is no information available at this time.

Capacity of palliative care workforce training in Universities and Medical Schools:

- Estonia has one medical school but this does not have mandatory training in palliative care.
- There are a few full professors who have some training in paediatric palliative care.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

Essential medications are available in Estonia.

Developments/opportunities/barriers relating to the accessibility of essential medications:

Essential medications are accessible in Estonia.

Developments/opportunities/barriers relating to the affordability of essential medications:

Essential medications are affordable in Estonia (but the system does not exist).

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to ‘opiophobia’:

There have been some initiatives to promote attitudinal change in relation to ‘opiophobia’ in Estonia.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

There is no information available at this time.

The impact of these policy changes and ways in which they have been important:

There is no information available at this time.

Development of a national palliative care consensus:

There is no information available at this time.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

There is no information available at this time.

Development of an advocacy framework for integrating palliative care into the health care system:

There is no information available at this time.

Strategies to improve political awareness and government recognition of palliative care:

There is no information available at this time.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

There is no information available at this time.

Involvement with the European Union in relation to hospice and palliative care initiatives:

There is no information available at this time.

Development of initiatives framing palliative care as a 'human right':

There is no information available at this time.

General legislation relating to palliative care:

There is no information available at this time.

Published national documents relating to palliative care standards and norms:

There is no information available at this time.

National Plan or Strategy of Palliative Care:

There is no information available at this time.

National Cancer Control Strategy:

There is no information available at this time.

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy in Estonia but it does not contain an explicit reference to palliative care provision.

National Primary Health Care Strategy:

There is no information available at this time.

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

There is no information available at this time.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- All doctors in Estonia can prescribe opioids.
- There are no pain guidelines in Estonia.

Funding of palliative care services:

- No payments are required for palliative care consultation or hospitalisation.
- Payment may be required for palliative care medication (depending upon specific circumstances).

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

There is no information available at this time.

Major public discussion, debate or controversy about hospice and palliative care:

There is no information available at this time.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

There is no information available at this time.

Hospice or palliative care 'success' stories:

There is no information available at this time.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is no information available at this time.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

A dedicated person is required to develop the system of palliative care in Estonia.

Most significant issues facing hospice and palliative care in the next three years:

There is no information available at this time.

Implications for palliative care relating to the current economic crisis:

There is no information available at this time.

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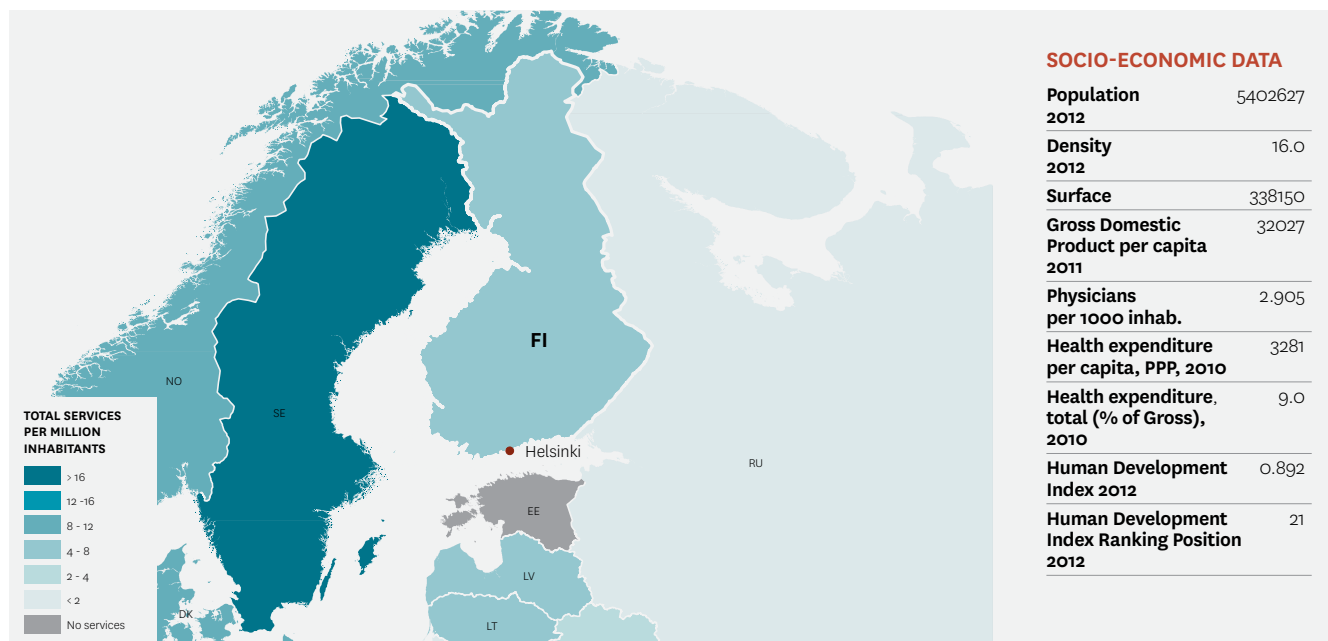
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 1 |
| Home palliative care support team | 12 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 2 |
| Palliative care units in non-tertiary hospitals | 4 (60) |
| Inpatient hospice | 4 (80) |
| Day hospice/day care centre | 2 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

There are no official figures; therefore all data are personal estimates/estimates provided by experts.

Additional comments:

- There are four hospices in Finland, all staffed by high-standard professionals and some volunteer workers also.
- In addition to the figures above, there are three small palliative care units in acute hospitals (but they usually work only one or two days per week); the small palliative care units are staffed by one doctor (once a week).
- In addition to the figures above, there are two day care centres.
- There is a day care center in Terhokoti-hospice, which is open 4-5 times per week and staffed by a doctor and registered nurses.
- There are two palliative care units in hospitals (Tampere and Helsinki).

Palliative care services for children:

There is no information available at this time.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|------------------|---|
| 1988 | The first Nordic hospice opens in Tampere, and the second hospice opens in Helsinki. |
| 1995-2000 | The number of pain units in hospitals steadily increases. |
| 2000-2005 | The development of professorship positions improves education relating to palliative care. |
| 2000-2005 | Palliative care units become established in University Hospitals. Palliative care is taken more seriously among doctors through University Hospital activity and education attempts to make it a medical specialty (not simply "nursing"). |
| 2000-2005 | A Nordic specialist course in palliative medicine is developed. |
| 2002 | The hospice in Turku opens. |
| 2004 | The Helsinki University Central Hospital mark the publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organisation of palliative care) by promoting the report at a number of educational events in an attempt to get palliative medicine established as a sub-specialty in Finland. |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- Palliative medicine became a "special competency" in 2007;
- A national two-year long program for specializing in palliative medicine began in 2007;
- Ongoing development of the Nordic Specialist Course in Palliative Medicine (since 2003);
- National guidelines on providing care for patients at the end-of-life were produced in 2008 and are to be updated in 2012.
- SPLY has contributed to all the above initiatives.

Overall progress in hospice and palliative care:

Hospice and palliative care has improved in Finland.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: Some part-time palliative care units have been opened in general hospitals.
- Nursing homes: Some nursing homes have trained their nurses in palliative care.
- Residential homes for the elderly: A lot of discussion has taken place relating to the provision of palliative care for dementia patients.
- Other community settings: A number of home care teams in primary care units (based in hospitals) now provide palliative care for patients at the end-of-life.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

- Most of the patients in palliative care are cancer patients (approximately 95%), but ALS patients are the second largest patient population.
- SPLY has promoted initiatives to emphasize the fact that other categories of patients at the end-of-life also require palliative care.

Perceived barriers to the development of hospice and palliative care:

(i) Unequal organisation of palliative care services across the country (ii) Lack of resources (iii) Attitudes among decision-makers – curative (successful) forms of medicine are usually preferred.

Perceived opportunities for the development of hospice and palliative care:

(i) Attitude towards hospice and palliative care among Finnish citizens is generally positive (ii) Training opportunities for doctors and nurses is increasing (and improving in quality) (iii) Much discussion about hospice and palliative care has taken place in the Finnish media.

Other issues relevant to the development of hospice and palliative care:

There is no information available at this time.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- The Finnish Association for Palliative Medicine (Suomen palliatiivisen lääketieteen yhdistys) was formed in 2003: the association has a website (<http://www.palliatiivisenlaaketieteenyhdistys.fi/>), and is representative of the whole country.
- The Finnish Association for Palliative Care (Suomen palliatiivisen hoidon yhdistys) was formed in 1995: the association has a website (<http://www.sphy.fi/>), and has representatives from the whole country.

Directory or catalogue of palliative care services:

There is no information available at this time.

Congresses, scientific meetings or scientific journals in palliative care:

- There is a palliative care national congress every year and there is a (non-scientific) journal "Palliative Care" (in Finnish), which publishes clinical articles.
- There is an annual spring meeting of the SPLY with a scientific program "Valtakunnalliset saattohoitopäivät". There are educational days of "multidisciplinary pain treatment" in Tampere once a year (two days).

Palliative care research capacity:

Researcher: Tiina Saarto, Helsinki University Central Hospital, Department of Oncology, Palliative Care Unit.

Palliative care collaboration:

Pioneers: The Finnish Association for Palliative Medicine; Finnish Association for Palliative Care.

Worldwide palliative care alliance level of development:

4A (Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision).

A number of home care teams in primary care units (based in hospitals) now provide palliative care. Initiatives have been developed that emphasize the need for palliative care for 'non-cancer' patients

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- Palliative medicine became a special competency in 2007;
- A national two-year long program for specializing in palliative medicine began in 2007;
- Ongoing development of the Nordic Specialist Course in Palliative Medicine (since 2003);
- There is a small amount of 'special competence' training for nurses (a pioneering initiative).

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Development varies between universities; some have organized courses on palliative care, but more often palliative care is included in the courses of other medical specialties (oncology, for example).
- Nursing: There has not been enough development in nursing under-graduate palliative care education; the number of initiatives have hardly increased since 2006.
- Social work: No developments.
- Other professions: No developments.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: As above.
- Nursing: Some high schools arrange courses in palliative care (there are more initiatives than in 2006).
- Social work: Social workers can take part in the palliative care courses arranged for nurses.
- Other professions: No developments.

Translation of palliative care documents or other materials:

There is no need for the translation of palliative care documents or other materials as most Finnish people can speak fluent English.

Initiatives to develop healthcare professional leadership in palliative care:

There is a fellowship program to develop healthcare professional leadership in palliative care at Tampere and Helsinki universities.

Officially recognized medical certification:

There is no officially recognized medical certification in Finland. However, there are other awards: specialist competency in palliative medicine (training includes 150 hours of theory and two years of clinical practice); and the Nordic Specialist Course in Palliative Medicine which received accreditation in 2007 (68 people have been accredited to date).

Capacity of palliative care workforce training in Universities and Medical Schools:

- There are five medical schools in Finland (source: national survey); two of them have mandatory courses in palliative care (one other has an optional course) (personal estimate).
- There is one "other category" of professor of palliative medicine in Finland (part time - 50%) (source: national survey).

Palliative medicine gained specialty status and a national two-year long program for specializing in palliative medicine began in 2007. National guidelines on providing care for patients at the end-of-life have been produced

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

All essential medications are available in Finland.

Developments/opportunities/barriers relating to the accessibility of essential medications:

All essential medications are accessible in Finland.

Developments/opportunities/barriers relating to the affordability of essential medications:

All essential medications are affordable in Finland.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

There has been training of doctors and nurses in this area and much discussion within the Finnish media.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

Cancer patients get opioids free of charge providing the medical company and Ministry of Social Affairs and Health agree on the price. There has been disagreement between them on occasions that has resulted in the threat to remove certain opioids from the list of essential medicines; in these situations (to date), pain and palliative care specialists have been consulted and an amicable solution has been reached.

Initiatives that consider access to essential medication as a legal and human right:

The issue of access to essential medication as a legal and human right has been discussed at length in the Finnish media.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- There have been important guidelines provided by the Ministry of Health: for example, the guidelines for palliative care (2003), and the cancer program (2010-20) (where palliative care was strongly emphasized).
- The funding of Finnish hospitals is now regionally (county)-based; it used to be government (country)-based, and this was better for palliative care patients because it was more equitable. This issue has been extensively discussed in the Finnish media.
- The law which guarantees people get treatment within three months does not apply to palliative care patients (it mainly relates to orthopedic and other surgical patients).

The impact of these policy changes and ways in which they have been important:

These policy changes have generated important discussion about a law on terminal care (although not much has happened in practice).

Development of a national palliative care consensus:

See above.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

Ministers have met with decision makers and taken part in palliative care/pain management meetings with other key stakeholders.

Development of an advocacy framework for integrating palliative care into the health care system:

The Ministry of Social Affairs and Health has published a report "Development of Cancer Treatment in Finland (2010-2020)" which contains an explicit reference to the provision of palliative care.

Strategies to improve political awareness and government recognition of palliative care:

There have been numerous meetings with government ministers and many media initiatives relating to palliative care.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

The Cancer Society of Finland has funded palliative care research. There are also some smaller organisations which have funded palliative care initiatives relating to, for example, training and education.

Involvement with the European Union in relation to hospice and palliative care initiatives:

The Ministry of Social Affairs and Health has regular contact with the EU; it is unclear whether palliative care has been on the agenda of these meetings.

Development of initiatives framing palliative care as a 'human right':

There have been a number of initiatives framing palliative care as a 'human right' (meetings with government ministers and widespread discussion within the mass media).

General legislation relating to palliative care:

There is no information available at this time.

Published national documents relating to palliative care standards and norms:

- Printed: Hyvä saattohoito Suomessa (Terminal care recommendations based on expert consultation), Ministry of Social Affairs and Health, Finland (first published 3.6.10).
- Online: www.stm.fi/ - web pages of Ministry of Social Affairs and Health, Finland (first published 3.6.10).

National Plan or Strategy of Palliative Care:

As above.

National Cancer Control Strategy:

The Ministry of Social Affairs and Health has published a report "Development of Cancer Treatment in Finland (2010-2020)" which contains an explicit reference to the provision of palliative care (2-3 pages).

National HIV/AIDS Strategy:

There is no information available at this time.

National Primary Health Care Strategy:

There is no information available at this time.

Designated policy maker for the delivery of palliative care services:

The Ministry of Social Affairs and Health.

Department of Health specific responsibility for the delivery of palliative care services:

The Ministry of Social Affairs and Health.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

Some of the hospices have an external auditing system and quality control systems.

Opioid legislation/Pain guidelines:

- All medical doctors are allowed to prescribe strong opioids (distributed from pharmacists).
- Pain guidelines: there are criteria/national guidelines for the treatment of pain in different diseases - Käypä hoito-suositus: Kuolevan potilaan oireiden hoito (www.kaypahoito.fi/web/kh/suosituksset/naytaartikkeli/tunnus/hoi50063).

Funding of palliative care services:

- There is partial payment required for palliative care consultation (as for all patients receiving healthcare services); for outpatient consultation the cost is approximately 10-30 euros;
- There is partial payment required for palliative care hospitalisation (as for all patients receiving healthcare services); for hospitalisation the cost is approximately 30 euros;
- There is no payment required for strong opioids (they are free of charge).

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006**Change in public awareness or perception of hospice and palliative care:**

There has been a change in public awareness and perception of hospice and palliative care; the concept of providing good-quality palliative care for people at the end-of-life is increasingly being accepted by the Finnish public.

Major public discussion, debate or controversy about hospice and palliative care:

There has been major public discussion about hospice and palliative care.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

There have been many media initiatives that seek to broaden awareness and understanding of hospice and palliative care.

Hospice or palliative care 'success' stories:

In general, people understand more about palliative care and it has become easier to discuss it as a "human right" (although there have not been any major 'success' stories as such).

Initiatives seeking the legalisation of euthanasia or assisted dying:

- This issue was discussed in the Finnish medical journal "Duodecim" in 2011.
- There have been many media initiatives seeking the legalization of euthanasia in 2012; there has been an official statement from the government that it is not totally ethically wrong to use euthanasia in some restricted cases (assisted suicide is not a crime in Finland).

Training opportunities for doctors and nurses is increasing (and improving in quality) and some nursing homes have trained their nurses in palliative care. Attitude towards palliative care is generally positive in Finland

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

In order to develop a national system of palliative care in Finland and ensure that it is accessible throughout all regions of the country, training in the discipline for nurses must be developed; there is a need for 10 nurses:1 doctor in palliative care consulting units in every central hospital throughout Finland.

Most significant issues facing hospice and palliative care in the next three years:

The national associations are key to the development of palliative care in Finland and must be active in every issue that arises in the field.

Implications for palliative care relating to the current economic crisis:

There is a greater need to emphasize that the provision of good-quality palliative care is not expensive on a long-term basis; patients at the end-of-life are not a new economic group - they already consume much of the health care system budget. It is therefore important to consider the most efficient and reasonable use of resources.

References

Kaasalainen V; Vainio A; Ali-Melkkilä T. "Developments in the treatment of cancer pain in Finland: the third nation-wide survey. *Pain*. 1997;70(2-3):175-83."

Tasmuth T; Saarto T; Kalso E. 2006. "How palliative care of cancer patients is organised between a University Hospital and primary care in Finland". *Acta Oncologica*; 45 (3): 325-31.

Vainio A. 1990. "Palliative care in Finland". *Palliat Med*;4:225-227.

France¹

NATIONAL ASSOCIATION

French Society of Accompaniment and Palliative Care

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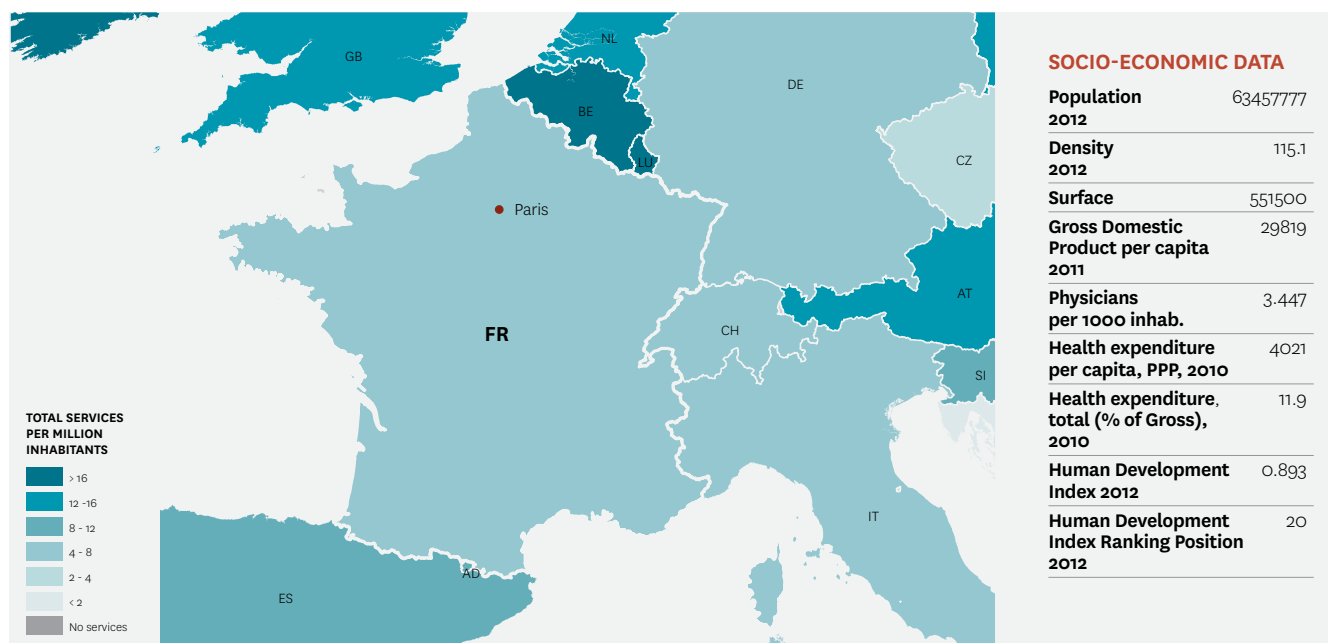
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 260-365 |
| Home palliative care support team | 118-124 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 107-114 (1176-1300) |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 0 |
| Day hospice/day care centre | 15 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- National Report 2010 - SFAP.
- First report of the French National Observatory on End-of-Life Care (www.onfv.org).

Additional comments:

- In addition to the 1300 PCU beds (in specific care units), 4900 PC beds have been implemented in 815 non-specific hospital departments such as oncology, pulmonology, geriatrics, ICU, gastroenterology or even long-term care units. These beds (between 3 and 6 per care unit) are dedicated to patients who need palliative care treatment but who don't need the complete resources of a palliative care unit.
- The concept of volunteerism is relatively unknown in France (and is socially not completely accepted).
- It is impossible to provide accurate data about "mixed palliative care support teams" as some palliative care teams provide home-based care but some do not; mixed teams are therefore included within the total number of hospital/home palliative care support teams
- Home palliative care support teams are known as networks called "Réseau" or "hospitalization at home"
- Palliative care units in non-tertiary hospitals are included in the total number of palliative care units in tertiary hospitals
- There are 17 'tertiary hospitals', 15 'geriatric' hospitals, and five 'geriatric/rehabilitation hospitals' that provide some form of palliative care.
- Until now, the development of day hospices/day care centres ("Hôpitaux de jour") has been limited since they had no status in the French health system and therefore no specific financing (Source: a recent memorandum from the Department of Health (2012)).

Palliative care services for children:

- There are 22 paediatric palliative care support teams (including four home palliative care support teams) (one in each region)
- There are 185 palliative care beds in paediatric departments (essentially in tertiary hospitals).

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

- 1986** Palliative care begins to develop in France.
- 1997** The “Kouchner” law is introduced to address the problem of uncontrolled pain as a health concern in France.
- 1999** First law on palliative care (and starting point of the French healthcare policy in the field of palliative care).
- 2002** The official document “Circulaire DHOS/O 2/DGS/SD 5D n°2002-98 du 19 février 2002: relative à l’organisation des soins palliatifs et de l’accompagnement en application de la loi n°99-477 du 9 juin 1999, visant à garantir le droit à l’accompagnement en soins palliatifs” is published.
- 2004** Société Française d’Accompagnement et de Soins Palliatifs (SFAP) marks the publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organisation of palliative care) by sending a copy of the report to all of its members, and placing the recommendations of the report on the SFAP web site.
- 2005** “Patients’ Rights and End of Life Care” Act (April 2005). This law brought new rights to patients and clarifies medical practices regarding end of life care: it allows withholding/withdrawal of life-support treatment, and intensified use of medications that may hasten death through a double effect, as long as hastening death is not the purpose of the decision. It also specifies the requirements of the decision-making process.

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- The number of hospices in PCUs has increased from 90 (942 beds) in 2007 to 107-114 (1176-1300 beds); the evolution of laws and support from the Ministry of Health have contributed to this increase.
- The number of PCUs has increased from 80 (825 beds) in 2005 to 107-114 (1176-1300 beds) in 2012. Additionally, the number of PC beds in other medical units has grown from 1900 beds in 2005 to 4900 in 2012.
- The resources of hospital palliative care support teams (260-365 in 2012) are currently being reinforced in order to facilitate intervention in care-homes and nursing-homes (“EHPAD”).
- 2008-2012: Third National Strategy for the development of palliative care in all settings [evaluation: full report].
- 2010: creation of the French National Observatory on End-of-Life Care. Its first mission is to produce data and qualitative information on actual medical practices at the end of life, in order to give the Health ministry, the Department of Health, the National Authority for Health and the National Accreditation Agency a better understanding of healthcare professionals’ needs and improve national priorities. Its second mission is to give the citizen, congressmen, decision makers and healthcare professionals a core of reliable information on End-of-Life Care in order to ease and to “appease” the public debate. Finally, the ONFV has been given the role of promoting research and facilitating cooperation between the different research centers in France.
- 2011: creation of a ‘Family Allowance’ (53 euros/day during 21 days) for the carers of dying patients who need to reduce their professional activities or to take leave for a few weeks: this temporary benefit from Social Insurance aims to ease the financial burden on family carers.

Overall progress in hospice and palliative care:

Hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: Palliative care beds are now available to patients in all types of hospital wards. This represents an increased financial contribution as funding is now being given to other types of services that provide palliative care. Hospital palliative care support teams have been created in almost all hospitals with more than 200 deaths per year.
- Nursing homes: There is legislation in this area: décret n° 2007-241 du 22 février 2007 relatif à l’intervention des structures d’hospitalisation à domicile dans les établissements d’hébergement pour personnes âgées/Décret modifiant le code de la santé publique (dispositions réglementaires) et le code de la sécurité sociale (deuxième partie: Décrets en Conseil d’Etat). Il définit les conditions d’interventions de l’HAD dans les EHPAD. Both hospital and home palliative care support teams have the possibility to go into nursing homes for elderly people. Around 62% of them regularly visit patients in such homes (2012). The spread of the “palliative care culture” in nursing homes has been targeted as one of the main challenges for the next National Strategy for End-of-Life Care.
- Residential homes for the elderly: As above.
- Other community settings: No development.

Expansion from a focus on cancer patients to address the needs of ‘non-cancer’ patients:

The National Plan of Palliative Care addresses the needs of ‘non-cancer’ patients.

Perceived barriers to the development of hospice and palliative care:

(i) Financial barriers (ii) Lack of doctors and nurses working in hospice and palliative care (iii) Traditional attitudes of medical professionals (iv) Late referrals to palliative care (v) GPs have little involvement with palliative care patients (vi) There are still some areas of France where palliative care is underdeveloped (especially for long-term patients) (vii) Lack of clinical and ethical guidelines for all healthcare professionals.

Perceived opportunities for the development of hospice and palliative care:

(i) National Plan of Palliative Care developed by the Government (ii) Palliative care training and education (iii) Changes to legislation (for example, the Law of 9th June 1999 relating to access to palliative care; the Law of 24th April 2005 relating to the rights of patients at the end-of-life) (iv) The financing of palliative care: Contrôles CNAMTS critères de décision pour les séjours de soins palliatifs en médecine ou chirurgie (court séjour) Critères de Décision Pour Contrôle du GHM 23Zo2Z Soins Palliatifs Correspondant aux GHS 7992 7993 7994 (Séjours GHM soins palliatifs); (v) the qualification of palliative medicine has been recognized at the academic level with six professorships in palliative medicine now established (vi) the development of new and innovative palliative care research (and researchers) (vii) next National Strategy for End-of-Life Care (mainly focused on palliative care at home and in nursing homes); (viii) development of professional guidelines for complex decision-making processes.

Other issues relevant to the development of hospice and palliative care:

Although there has been an increase in the number of palliative care beds, this has not been at the specialized level (dedicated palliative care beds).

The number of hospices in palliative care units and beds in other medical units has increased; resources of hospital palliative care support teams have been increased to provide palliative care in residential homes and nursing homes

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

The French Society of Accompaniment and Palliative Care (Société Française d'Accompagnement et de Soins Palliatifs), was formed in 1990. The society has a website (www.sfap.org), and is representative of the whole country.

Directory or catalogue of palliative care services:

There is an online directory of palliative care services: www.sfap.org (first published online in 2010).

Congresses, scientific meetings or scientific journals in palliative care:

- The Congress National de la SFAP is held annually and attracts approximately 3,000 people.
- The journal *Médecine Palliative* is published monthly (but has no database index).

Palliative care research capacity:

- Although many research centers report conducting palliative care research, there are very few publications; research centers tend to be composed of isolated people rather than structured research frameworks (for example, observatoire national de la fin de vie).
- French National Observatory on End-of-Life Care (first created in 2010): www.onfv.org [contact : Lucas Morin l.morin@onfv.org / 33(0)153753324]
- Palliative care researchers include: Frederic Guirimand (frederic@guirimand.fr); Gisele Chvetzof (CHVETZOFF@lyon.fnclcc.fr); Guillemette Laval (GLAVAL@chu-grenoble.fr); Wadih Rhondali (wadih.rhondali@chu-lyon.fr); Bernard Wary (bernardwary@wanadoo.fr); Marilene Filbet; Philippe Poulain (phpoulain@wanadoo.fr); Laure Copel; Chantal wood.

Palliative care collaboration:

- There is palliative care twinning between French organizations and ones in the Congo and Romania.
- Initiatives to celebrate World Hospice and Palliative Care Day are held by SFAP.

Worldwide palliative care alliance level of development:

4B (Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision).

A National Strategy for the Development of Palliative Care has been produced that also addresses the needs of 'non-cancer' patients. The French National Observatory on End-of-Life Care has been established

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- The recognition of palliative medicine as a medical "speciality".
- Creation of a national post-graduate training program.
- PCUs have been recognised as "Certified training units" for oncology medical students.
- Upcoming creation of a "Master of Palliative Medicine" (2013).

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Palliative care is now included in the curricula of first-year medical students; palliative medicine as a speciality continues to develop; there are six chairs in palliative medicine.
- Nursing: Palliative care is included in nursing school curricula.
- Social work: Palliative care is included in a number of social work courses.
- Other professions: Many universities have their own specific training courses relating to palliative care (social sciences).

Specific developments in post-graduate palliative care education initiatives:

- Medicine: The development of DESC (Diplôme d'Etudes Spécialisées Complémentaires). Creation of a national post-graduate training program ("Diplôme d'Etudes Spécialisées Complémentaires").
- Nursing: No specific development.
- Social work: No specific development.
- Other professions: No specific development.

Translation of palliative care documents or other materials:

There have been a few palliative care documents translated (but there is a need for more translation of materials).

Initiatives to develop healthcare professional leadership in palliative care:

- Initiatives to develop healthcare professional leadership in palliative care have taken place in hospitals and within the wider community (continuous training).
- Creation of six 'Palliative Medicine' professorships in five different regions of France.
- Implementation of "Referring physicians" (normally certified by a two-year training course) in all hospital wards with palliative care beds.

Officially recognized medical certification:

- Since 2008, palliative care has been officially certified as a Sub-specialty by University medical schools; the certification is "Diplôme d'étude Spécialisée Complémentaire (DESC) Médecine Palliative et Médecine de la Douleur". All medical specialties are accepted as qualifying for the Sub-specialty. Accreditation consists of two years training – six months studying pain management in a pain clinic and eighteen months in a palliative care unit. Approximately 35 healthcare professionals receive accreditation each year.
- Another form of accreditation is a university diploma in palliative care, which has been available to both physicians and non-physicians since 1992 (approximately 800 people each year receive accreditation in this way).

Capacity of palliative care workforce training in Universities and Medical Schools:

- In France, all medical schools have palliative care as a compulsory component of their curricula (16 hours in total including pain management and bereavement studies at both under- and post-graduate level).
- There are six "other category of professors" in palliative medicine in five different regions (in charge of the development of post-graduate training-courses).

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

There are no restrictions to the availability of essential medications in France.

Developments/opportunities/barriers relating to the accessibility of essential medications:

There are no restrictions to the accessibility of essential medications in France.

Developments/opportunities/barriers relating to the affordability of essential medications:

Essential medications are always reimbursed to the patients through social health insurance (although the new format of opioids has made them more expensive); there may be barriers to affordability at the hospital pharmacies.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There have been no new initiatives to change regulations that may restrict physician or patient access to pain relief since 2006; legal accessibility of opioids and benzodiazepines is not a problem in France (although control of the distribution of opioids remains very strict).

Initiatives to promote attitudinal change in relation to 'opiophobia':

- The 2005 "Patients' Rights and End of Life Care" Act increased the obligation to treat pain (even if the intensification of analgesic medications may have a "double-effect").
- Guidelines of the French National Authority for Health ("HAS") on pain treatment and sedation.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

- All economically disadvantaged persons get free access to opioid medication (all medications are fully reimbursed).
- Upcoming: national pilot-study on "End-of-Life of patient with social and economic insecurity" (2013).

Initiatives that consider access to essential medication as a legal and human right:

The 1999 and 2005 Laws considered access to essential medication as a legal and human right.

There has been an increase in palliative care training and education initiatives and six professorships in palliative medicine are now established. There have been changes to palliative care legislation and the financing of palliative care has improved

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- There have been three National Strategies (1999-2001/2001-2003/2008-2012) and two Laws that have affected the development of hospice and palliative care in France.
- Recent creation of a 'Family Allowance' (53 euros/day during 21 days) for the carers of dying patients who need to reduce their professional activities or to take leave for a few weeks: this temporary benefit from Social Insurance aims to ease the financial burden on family carers.

The impact of these policy changes and ways in which they have been important:

These legal and policy changes have had an impact on palliative care structures, training and education initiatives and research development.

Development of a national palliative care consensus:

A national palliative care consensus has been developed through medical guidelines (cancer pain, symptoms, sedation), and the creation of a French National Observatory on End-of-Life Care (directly linked to the Ministry of Health).

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

- Significant meetings with stakeholders and policy makers to develop palliative care strategies include the annual National Congress; the Francophone International Congress; the National Workshop for discussing specific aspects of palliative care; the regional "day of palliative care"; and the "mission for Palliative care" (Arrêté du 6 juin 2006 relatif à la désignation des membres du Comité national de suivi du développement des soins palliatifs et de l'accompagnement de la fin de vie).
- A National Committee for the Development of Palliative Care was created in 2006, in order to elaborate and implement the 3rd national strategy on palliative care (2008-2012). This committee facilitates discussions between decision-makers and palliative care healthcare professionals (two plenary meetings each year, in addition to topic-centered workshops).
- Decision and policy makers are invited to join the annual National Congress of the French Society of Palliative Care and the Francophone International Congress on Palliative Care.
- Since 2010, a national joint-action "Quality & End-of-Life Care" between the French Observatory on End-of-Life Care and the National Authority for Health is implemented, mainly focused on professional guidelines and hospital accreditation. In 2012-2013, all major national medical societies (including the SFAP) are invited to work on professional guidelines about (1) Medical decision-process at the End-of-Life; (2) Early identification of palliative care patients; (3) Medical futility and unreasonable pursuit of treatments in advanced phase of a serious illness; (4) Avoiding burnout of the healthcare professional facing end-of-life situations.

Development of an advocacy framework for integrating palliative care into the health care system:

Palliative care is already integrated into the health care system (two new Laws have been included in the Public Health Code).

Strategies to improve political awareness and government recognition of palliative care:

- Strategies to improve political awareness and government recognition of palliative care include an increased media presence; the communication task force within SFAP; the organisation of meetings, public debates, etc.
- One of the missions given to the French National Observatory on End-of-Life Care is to give the citizen, congressmen, decision makers and healthcare professionals a core of reliable information on End-of-Life care in order to ease and to "appease" the public debate. It publishes (each year in March) a full report on the situation of End-of-Life care in France.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

There have been many palliative care funding initiatives by individual Foundations and private donors; government funding is provided through the following legislation: Programme de développement des soins palliatifs 2008-2012 présenté par le Président de la République ce vendredi 13 juin au Centre Hospitalier de Bourges Circulaire N°DHOS/O2/2008/99 du 25 mars 2008 relative à l'organisation des soins palliatifs Décret n° 2007-573 du 18 avril 2007 relatif au congé de soutien familial et modifiant le code du travail (3ème partie: Décrets) et le code de la sécurité sociale (3ème partie).

Involvement with the European Union in relation to hospice and palliative care initiatives:

Participation in the task-force of the European Council "Decision-making process regarding medical treatment in end of life situations".

Development of initiatives framing palliative care as a 'human right':

Initiatives framing palliative care as a 'human right' include: Le Collectif "Plus Digne la Vie": ("More dignity in life"); the "Right of precariousness and vulnerability"; the philosopher Hirsh created the "day of human rights" (although these initiatives were not very well disseminated).

General legislation relating to palliative care:

- 1999: "Equal access to palliative care" Act: this law stresses that doctors safeguard the patient's dignity by ensuring palliative care
- 2005: "Patients' rights and the end of life" Act: The doctor "must strive to relieve the suffering of the patient by means appropriate to his state and to give him moral support"
- 2008: Department of Health's official instructions on the organisation of palliative care: These instructions detail the missions, goals, organisation and functioning of every French palliative care structure
- 2010: Creation of a 'Family Allowance' (53 euros/day during 21 days) for the carers of dying patients who need to reduce their professional activities or to take leave for a few weeks: this temporary benefit from Social Insurance aims to ease the financial burden on family carers.

Published national documents relating to palliative care standards and norms:

National documents relating to palliative care standards and norms have been published as both a printed and online version (available on the SFAP website).

National Plan or Strategy of Palliative Care:

National Strategy for the Development of Palliative Care (2008-2012)

[See the full report]

National Cancer Control Strategy:

There is a National Cancer Control Strategy (INCA) but it doesn't include any public-health targets or actions related to palliative care.

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy but it doesn't include any public-health targets or actions related to palliative care.

National Primary Health Care Strategy:

There is a National Primary Health Care Strategy but it does not contain an explicit reference to the provision of palliative care.

Designated policy maker for the delivery of palliative care services:

- There is a designated policy for the delivery of palliative care services: Plan de Développement des Soins Palliatifs.
- French General Directorate for Provision of Healthcare ("Direction Générale de l'Offre de Soins").
- General Directorate of Higher Education and University Research ("Direction générale de l'enseignement supérieur et de la recherche").

Department of Health specific responsibility for the delivery of palliative care services:

The French General Directorate for Provision of Healthcare has specific responsibilities for the delivery of palliative care services [R4 Office: Public Health Strategies and specific populations].

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

- French National Authority on Health (HAS) assesses security and quality of care (including palliative care).
- Health Regional Agencies (ARS) ensure palliative care provision.

Opioid legislation/Pain guidelines:

- Opioids are available in a secure form of prescribing. All cancer patients are 100% reimbursed for the cost of opioids.
- Pain guidelines are available online (on the SFAP website).
- Sedation guidelines have been published in 2009 (HAS).

Funding of palliative care services:

- For the patient: There is no payment required for palliative care consultation, hospitalisation, or medication.
- Hospital-based palliative care is financed through specific DRGs (PCUs and palliative care beds in medical units) or through the global budget (hospital and home palliative care support teams).
- Special funding is available for home-based palliative care.

Initiatives framing palliative care as a 'human right' include: Le Collectif "Plus Digne la Vie": ("More dignity in life"); the "Right of precariousness and vulnerability"; the philosopher Hirsh created the "day of human rights" (although these initiatives were not very well disseminated)

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

There has been a change in public awareness and perception of hospice and palliative care because more people know someone who died in a hospice.

Major public discussion, debate or controversy about hospice and palliative care:

- There is a strong debate on End-of-Life Care, Assisted suicide and Euthanasia in France (25 opinion polls and approximately 30 law-projects since 1990).
- In 2012, new-elected President François Hollande started a "National Commission on End-of-Life", which published its report on December 2012 [Full report]

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

- Initiatives that seek to broaden awareness and understanding of hospice and palliative care have been developed by volunteer groups, the SFAP and local associations (for example, communication of the 2005 Law).
- A film was made called "les yeux ouverts" that described life in a hospice.

Hospice or palliative care 'success' stories:

There is no information available at this time.

Initiatives seeking the legalisation of euthanasia or assisted dying:

- 30 Law-projects have been proposed to legalize euthanasia since 1990.
- Laws have been proposed to decriminalize euthanasia; August 2009 National Assembly; November 2009; Senate January 2011; Senate January 2012; Senate Legalisation of Euthanasia is included in the programme of the recently-elected French President.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

- There has been an increase in the number of patients affected by chronic illness, and elderly and paediatric palliative care patients. If the current level of development was to continue, approximately 300,000 people would require some form of palliative care each year (but only approximately 150,000 people would actually receive it).
- There is not a clear understanding about the level of palliative care that is required or the settings within which it should be provided; the place of dedicated palliative care beds still also remains unclear.
- Further academic development is required to promote more research in the field of palliative care.

Most significant issues facing hospice and palliative care in the next three years:

- Research in the field of palliative care; care of the elderly; home-based palliative care.
- The pro-euthanasia lobby is very powerful.
- Many physicians are still sceptical about palliative care.
- Many patients who wish to die at home die in hospital (only 25% of deaths occurred at home in 2010).

Implications for palliative care relating to the current economic crisis:

- Training and education should be developed to enable volunteers to assist health-care professionals (rather than simply listening to patients, asking the public for donations, etc.).
- Community outreach needs to be developed.
- Financial cutbacks have already occurred amongst PCU staff.

There has been an increase in the number of patients affected by chronic illness, and elderly and paediatric palliative care patients. If the current level of development was to continue, approximately 300,000 people would require some form of palliative care each year (but only approximately 150,000 people would actually receive it)

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Georgia¹

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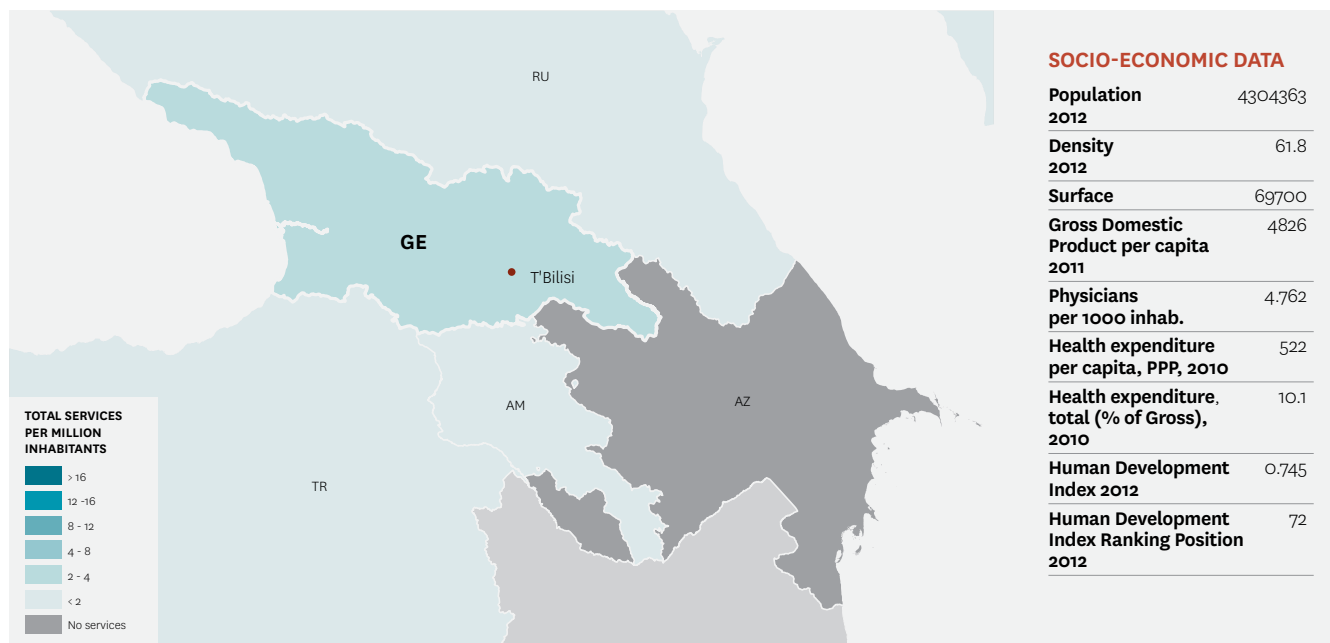
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 1 (5) |
| Hospital palliative care support team | 1-2 |
| Home palliative care support team | 13-16 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 1 (15) |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 1-2 (19-22) |
| Day hospice/day care centre | 1 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Tamari Rukhadze
- Ioseb Abesadze
- Rema Gvamichava
- Tamar Gotsiridze (Mother Nino)

Additional comments:

- The Cancer Prevention Centre (CPC) founded the first inpatient palliative care unit in Georgia (currently operating 22 beds). CPC is an affiliated facility of Tbilisi State Medical University.
- Palliative care services are one of the services provided by the National Cancer Centre of Georgia, an affiliated clinic of Iv. Javakishvili Tbilisi State University.
- Mercy Center at Transfiguration Monastery Convent was founded in 2003; presently it operates as a hospice (7 beds) and provides home-based care for patients in Tbilisi. It also runs an accredited college for nurses.
- Home-based palliative care is provided in Tbilisi (6 teams), Kutaisi (3 teams), Zugdidi (3-4 teams), Telavi (2 teams) and Ozurgeti (1 team) and Gori (1 Team).
- There is one palliative care unit in a tertiary hospital (in Tbilisi).
- There are two inpatient hospices (one in Tbilisi and one in Zugdidi).

Palliative care services for children:

- There are four paediatric home palliative care support teams; CPC is providing paediatric home-based palliative care in Tbilisi (3 teams) and Zugdidi (1 team).
- The National Cancer Centre of Georgia and CPC provide paediatric palliative care services.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

- 1999-2005** Round table meetings and discussions about palliative care commence in the Ministry of Labour, Health and Social Affairs. Meetings with pharmaceutical companies are also conducted.
- 1999-2005** The experience of countries with well-developed palliative care systems are adapted and presented for discussion in the Parliament of Georgia.
- 2000-2001** Two workshops on "Integrative Medicine in Palliative Care" were organized by Palliative Care Association "Humanists Union" (currently – Georgian National Association for Palliative Care).
- 2002-2005** A palliative care needs assessment for Georgia is conducted, revealing great interest in the establishment of palliative care services.
- 2002-2005** Three 'International Workshops on Palliative Care' are conducted in Georgia.
- 2002-2005** "Palliative Care: Medical and Organizational Aspects" is prepared and published in the Georgian language, introducing the main aspects of symptom control and pain management. The guideline is reviewed by the National Council on Bioethics and recommended as a supplementary study book for students of medical universities.
- 2003** The First Congress of Georgian Physicians sets up a 'Continuous Medical Educational' system involving 209 accredited programs that award physicians credits for the continuation of professional activities. Two programs ("Pain Management in Terminally Ill Patients" and "Symptom Control in Terminally Ill Patients") are prepared and presented by CPC and the Palliative Care Association "Humanists Union".
- 2004** CPC begins to function as a palliative care unit (as part of the State Program of Oncology).
- 2004** The Association of Humanists Union began to provide home-based Palliative Care Services to cancer patients at home through the "Mobile Palliative Care Team".
- 2004** CPC marks the publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organization of palliative care) by translating the publication into the Georgian language and distributing 500 copies to Georgian healthcare professionals. Presentations of the publication are conducted at the National Cancer Centre in Tbilisi, and at oncology hospitals in Kutaisi and Batumi. Policy makers from the Ministry of Labour, Health and Social Welfare, and the Healthcare Committee of the Parliament of Georgia are invited along with physicians, nurses, representatives of the Committee of Bioethics, and the mass media.

(…)

(…)

- 2005** An International workshop "Palliative Care Development in Georgia" is conducted, in conjunction with oncologists from Armenia and Azerbaijan.
- 2006** CPC commences its home care programme – it provides services not only to cancer patients, but also to socially unprotected groups of patients with "incurable diseases".
- 2006** CPC increases the number of beds in its palliative care unit from ten to 12.

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- A basis for the development of palliative care as an integral part of the National Healthcare System was created in Georgia (2006-2011) (through the collaboration with governmental institutions, NGOs and international organizations);
- In April 2007, the Parliament of Georgia approved the amendments to four laws relating to palliative care (<http://www.parliament.ge>);
- Between 2008-2010, the Minister of Labor, Health and Social Affairs (MOLHSA) issued four normative orders approving "Instructions for Palliative Care" and liberalizing opioid prescription and availability;
- The National Model of Palliative Care - Incorporation into the Healthcare System was presented by the National Palliative Care Coordinator and accepted by the Healthcare and Social Issues Committee of the Parliament of Georgia in April 2009;
- Between 2009-2010, the Georgian National Program for Palliative Care Action Plan (2011-2015) was prepared - it was approved by the Healthcare and Social Issues Committee of Parliament of Georgia in July 2010;
- Four papers have been published in international journals with impact-factor;
- More than ten grants from Georgian and international sources – for example, Open Society Institute (OSI), Open Society Foundation Georgia (OSGF), Help the Hospices (HtH, etc.) have been obtained;
- Videos on palliative care have been screened by national TV channels;
- Two movies have been screened at various events ("Social support - Lawyer services in a Palliative Care unit"; "Barriers to chronic pain management");
- More than 20 information meetings have been conducted in Tbilisi and different regions of Georgia, dedicated to the further development of palliative care (some of them with the participation of international experts);
- In 2007, six bulletins of palliative care were issued to medical professionals by CPC;
- Special newspapers (four editions) dedicated to different aspects of palliative care and aiming to increase public awareness were also issued;
- In 2010, a joint declaration of the Georgian National Association of Palliative Care (GNAPC), the Georgian Medical Association and medical students was prepared and signed – the declaration encouraged the Government to integrate palliative care into the Georgian National Healthcare System;
- There was a significant increase in the provision of palliative care services throughout the country (2006-2013).

There has been a significant increase in the provision of palliative care services throughout the country and an expansion from a focus on cancer patients to address the needs of 'non-cancer' patients

Overall progress in hospice and palliative care:

The capacity and quality of hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: The inpatient palliative care unit of CPC increased its number of beds from 12 to 22. The inpatient palliative care services in National Cancer Center increased its number of beds to 22.
- Nursing homes: There is no information available at this time.
- Residential homes for the elderly: There is no information available at this time.
- Other community settings: A day care centre for elderly people operated by foundation "Taoba" and association "Home Care in Georgia" has been opened.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

- Since 2006, the program "Palliative Care for HIV/AIDS Patients" has been initiated within the framework of a comprehensive program funded by "Global Fund against AIDS, TB and Malaria." Currently this program is operating in the capital, Tbilisi, and three other regions of the country;
- In 2012, palliative care programs (currently covering approximately 15% of the population and financed by governmental budget) are expanding from a focus on cancer patients to address the needs of 'non-cancer' patients with chronic incurable diseases;
- According to the Georgian Government Decree (statement N77) from 2011 the national program for providing the population with specific medications also covers the needs of non-cancer patients (previously it only covered the needs of cancer patients).

Perceived barriers to the development of hospice and palliative care:

(i) Lack of knowledge and human resources (ii) Lack of finances (iii) Imperfect regulations

Perceived opportunities for the development of hospice and palliative care:

(i) Good advocacy and political support (ii) Several high-qualified specialists in the field of palliative care (who train other healthcare professionals) (iii) Different institutions (foundations, associations, NGOs national health centres, universities) are highly motivated to develop palliative care.

Other issues relevant to the development of hospice and palliative care:

- Permanent international/national support from: OSI, OSGF, European Association for Palliative Care (EAPC), European Society of Medical Oncology (ESMO), International Association of Hospice and Palliative Care (IAHPC), etc;
- Implementation of Georgian National Program for Palliative Care;
- In 2008, the commencement of palliative care (inpatient and home-based care) for HIV/AIDS patients;
- Establishment of the Institute for Cancer Prevention and Palliative Medicine;
- Recognition of CPC as an ESMO designated centre of Integrated Oncology and Palliative Care in 2011;
- Establishment of the Georgian National Palliative Care Academy and International Palliative Care Research-Training Centre;
- Accreditation of the palliative care service of the National Cancer Centre as an ESMO Designated Centre of Integrated Oncology and Palliative Care (2011);
- Increased palliative care coverage throughout many regions of Georgia (provided by the National Cancer Centre).

Vitality

THE VITALITY OF PALLIATIVE CARE**National Associations of Palliative Care:**

Palliative Care Association "Humanists Union" was red as Georgian National Association for Palliative Care (GNAPC) in 2009; the association has a website (www.palliativecare.org.ge) and is representative of the whole country.

Directory or catalogue of palliative care services:

A directory or catalogue of palliative care services is in process.

Congresses, scientific meetings or scientific journals in palliative care:

- International workshop in palliative care for South Caucasian countries (Georgia, Azerbaijan, Armenia) in 2006, organized by CPC (with the participation of international experts);
- Master Class in Palliative Care for Black Sea countries organized by CPC and European School of Oncology (ESO) in 2008.

Palliative care research capacity:

- Georgian National Association for Palliative Care (www.palliativecare.org.ge);
- Georgian National Academy of Palliative Care – Educational-Training and Research Centre.
- The Institute for Cancer Prevention and Palliative Medicine.
- Department of Oncology and Palliative Care of Tbilisi State University.

Palliative care collaboration:

- Tamari Rukhadze – ESMO Palliative Care Working Group Member (since 2008); EAPC Spiritual Care Working Group Member (since 2010); the palliative care service of the National Cancer Centre participates in international study – for example, the European Palliative Care Cancer Symptom Study (EPCCS);
- The Pain and Policy Studies Group (Wisconsin, USA) (PPSG) assists and supports in the development of Georgian national opioid legislation;
- In preparation for the 2011 World Hospice and Palliative Care Day, CPC (in collaboration with OSFG) delivered a presentation at the American Academy of Tbilisi (AAT) (on September 30th, 2011) about the concept of palliative care. The AAT students received an invitation to join the activities on October 8th 2011. CPC also used the event to invite policy makers, healthcare providers and insurance companies to raise awareness about the benefits of palliative care for those living with life-limiting illnesses.
- Representative of CPC, Ioseb Abesadze, was invited as an international expert to celebrate 2012 World Hospice and Palliative Care Day in Yerevan, Armenia and delivered a presentation about palliative care development in Georgia.
- President of GNAPC – Dimitri Kordzaia was invited for technical Assistance and Expertise of Palliative Care National Program of Tajikistan (2011-2012), as invited lecturer on OSI seminars in Barcelona (Spain), Budapest (Hungary) and Brasov (Romania) in 2010-2012.

Worldwide palliative care alliance level of development:

4A (Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision).

Palliative care has become an integral part of the national health care system through collaboration with governmental institutions, NGOs and international organizations. Several high-qualified specialists in the field of palliative care train other healthcare professionals

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- Georgian-language handbooks and educational materials have been prepared and published;
- Three accredited Continuing Medical Educational (CME) programs in palliative care have been prepared and implemented; the courses were accredited by the Counsel of Continued Medical Education and Professional Development. More than 500 healthcare professionals have attended these programs throughout Georgia;
- Eight Georgian representatives have participated in "Salzburg Seminars for Palliative Care";
- More than 20 medical professionals have participated in multiple international congresses, conferences, study courses and policy meetings in different countries; more than 40 presentations and abstracts have been submitted;
- Dr. Irina Tsirkvadze passed the educational/bed-side training course in pediatric palliative care in Latvia under the supervision of Dr. Anda Jansone;
- Dr. Pati Dzotsenidze was elected as a fellow of the International Pain and Policy Study Group fellowship program;
- The international OMI satellite seminar (funded by OSI-OSGF): "Palliative Care in Children and AIDS" – was organised in Tbilisi (November 6-7, 2007);
- In 2008, a Georgian representative attended a one-month Fellowship – within the framework of the ESMO Palliative Care Research Program – in Barcelona, Spain;
- In 2008, the "Georgia-Ukraine – Provision of Adequate Pain Management and Drug Availability for Patients" – palliative care study was organized in Tbilisi and Kiev (organised by CPC, financed by OSGF). Topics of pain management and opioid availability were discussed with the participation of key stakeholders;
- Since 2009, an obligatory course in palliative care has been conducted for the post-graduate education of family physicians;
- In 2009 and 2010 the "Institute of Cancer Prevention and Palliative Medicine" and "Georgian Academy of Palliative Care" were founded as educational and research institutions in the field of palliative care (for Georgian and foreign medical professionals);
- Obligatory courses in palliative care were established in Iv. Javakhishvili Tbilisi State University and Tbilisi State Medical University for medical students and general nurses as well as in two Nursing Colleges in Tbilisi;
- In 2010, two medical doctors (Dr. Tamar Rukhadze and Dr. J. Abesadze) each completed a three-year educational course at the Institute of Palliative Medicine at San Diego Hospice, CA, USA and received the certificate of International Expert in Palliative Care;
- In March-April, 2011 another three medical doctors (Dr. Mariam Velijanashvili, Dr. Giorgi Metivishvili and Dr. Tamar Gotsiridze (Mother Nino)) started the same course at the Institute of Palliative Medicine at San Diego Hospice, CA, USA;
- In 2011, the Institute of Cancer Prevention and Palliative Medicine conducted training initiatives (financed by OSI) for primary Care physicians (village doctors) in pain management in two regions of Georgia (up to 150 participants); these initiatives continued (financed by OSGF) in another two regions of Georgia (up to 250 participants);
- In 2011, a Georgian representative (Dr Giorgi Metivishvili, physician, CPC) attended a one-month Fellowship in Israel within the framework of the ESMO Palliative Care Research Program;
- In 2011, the Georgian Academy of Palliative Care conducted educational/training courses for medical doctors and nurses from Tajikistan and Kyrgyzstan.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: See above
- Nursing: See above
- Social work: The Georgian Association of Social Workers in collaboration with CPC and the Institute for Cancer Prevention and Palliative Medicine are working to develop a palliative care curriculum for social workers (student social workers have placements in the inpatient unit of CPC);
- Other professions: palliative care education has been discussed in relation to clinical pharmacology and psychology.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: There is a special module of Palliative Care in a residential courses of "Family Medicine" and "Oncology" and short courses in Basics of Palliative Care, Chronic Pain Management and Symptom Control in residential courses of all specialties.
- Nursing: There is no information available at this time.
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Translation of palliative care documents or other materials:

- The "Recommendations of European Council on Palliative Care" (2003) have been translated and published (www.palliativecare.org.ge);
- The report of Jan Stjernsward (WHO and OSI International expert) – "Georgia National Palliative Care Program" has been translated and published (2005) (www.palliativecare.org.ge);
- Some chapters from a textbook of palliative care (by different authors) have been translated and compiled (www.palliativecare.org.ge);
- ESMO clinical practice recommendations for cancer pain and supportive care have been translated (www.palliativecare.org.ge);
- WHO recommendations for ensuring balance in national opioid control policy (2000) have been translated; (www.palliativecare.org.ge);
- WHO recommendations for ensuring balance in national policy of controlled medications (2011) have been translated (www.palliativecare.org.ge);

Initiatives to develop healthcare professional leadership in palliative care:

- See above re: International Palliative Care Fellowship (San Diego Hospice).

Officially recognized medical certification:

- Since 2006, palliative care has been afforded the status of Sub-specialisation within the following disciplines: oncology, family medicine, geriatrics, internal medicine, neurology. More than 50 healthcare professionals have been accredited in this way.
- Other awards include: postgraduate educational course in general palliative care; postgraduate educational course in pain management; postgraduate educational course in symptom control (approximately 14 healthcare professionals have been accredited in this way).

Capacity of palliative care workforce training in Universities and Medical Schools:

- There are an estimated ten medical schools in Georgia - there are four State medical schools (the other medical schools are private);
- At Tbilisi State Medical University (www.tsmu.edu.ge/), two mandatory courses of palliative care are included in both medical curricula (since 2006 – 1 ECTS within the framework of oncology) and nursing curricula (since 2011 – 5 ECTS);
- Two mandatory courses of palliative care (2 ECTS) are available at the Faculty of Medicine of Iv. Javakhishvili Tbilisi State University since 2008 (www.tsu.edu.ge/en/);
- Educational palliative care courses are implemented in nursing colleges (<http://www.medicine.tsu.ge/sabakalavro/samk%20oprograma.pdf>);
- There is one full professor of palliative medicine; there are also two assistant professors and three "other category of professors" of palliative medicine.

Since 2006, palliative care has been afforded the status of Sub-specialisation within the following disciplines: oncology, family medicine, geriatrics, internal medicine, neurology. More than 50 healthcare professionals have been accredited in this way

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- In 2006, only injectable morphine was available under the national health program for patients with chronic pain. On March 17th 2009, a policy round table (approximately 40 to 50 attendees) dedicated to improving opioid availability and oral morphine importation was organized with the participation of members of Parliament, representatives of MOLHSA, organizations providing palliative care, WHO Country Office, National Cancer Centre, AIDS Centre, the mass media and international experts: Mary Callaway, Karen Ryan, Katalin Muzsbek, and Martha Maurer. Special recommendations to the Ministry of Health were prepared.
- Due to the advocacy work undertaken in 2009, the government launched tender procedures for the procurement of oral forms of morphine; though sustained release oral forms of morphine were procured and imported in 2009, the procurement of immediate release forms still remained a problem (in spite of annual tender procedures for procurement - in 2011 it was tendered for three times). The most obvious reason for the failure of tender procedures was related to the price of the immediate release forms of oral morphine. However, in Spring 2012, importers took responsibility to import and as a result, immediate-release forms of oral morphine became available in Georgia in November 2012;

Developments/opportunities/barriers relating to the accessibility of essential medications:

- Amendments to Laws regulating the legal use of opioids places an obligation on the Georgian government to provide patients with the required amount and necessary forms of opioids, corresponding to international standards;
- On July 10 2008, MOLHSA signed the normative order changing the rules of opioid prescription; through increasing opioid supply from three to seven days; through cancelling the commission for signing and prescribing opioids; and through authorizing it as the responsibility of one physician only (with the supervision of the head of the medical facility (157/n);
- Several activities were performed within the framework of the following projects: 10.12.2008 - 10.06.2009 - to facilitate implementation of internationally acknowledged palliative care standards for chronic "incurable patients" in the national healthcare system by focusing on medical, legal, bioethical and human rights aspects of palliative care - education courses in Tbilisi for primary healthcare professionals; 1.03.2010 - 31.07.2010 "Improving the quality of life of chronic "incurable" patients by providing educational training in Palliative Care and Pain Management" (in five regional centres of Georgia);
- In 2010, three new decrees were issued by MOLHSA; N17 and N 18 regarding prescribing where two opioids or two different formulations of the same opioid can be prescribed in conjunction with one other (which allows the physician to prescribe immediate- and slow-release formulations together, so as to be sure that breakthrough pain can be adequately managed) and the third - N55/n according to which the village family doctor can get authorization to prescribe opioids without any supervision or any additional signatures on the prescription;
- According to Georgian Government decision N77, the national health program from 2011 also covers the needs of opioid analgesics for non-cancer patients;
- Amendments to Law "Narcotics, Psychoactive substances, Precursors and Narcological Aid" were undertaken in Spring 2012, according to which:
 1. The stigmatizing term "somatonarcoman" (patient who has dependence syndrome) was removed and replaced with a more appropriate definition;
 2. A new definition of "dependence" was introduced ("physical dependence" as a sole criteria for the diagnosis of dependence was removed);
 3. A paragraph concerning opioid use for medical reasons was added to the first Chapter of the law, reflecting the main principles and regulations relating to the law.
- In 2011, pain management was included in all residency programs for post-graduate students;

- In 2011, pain management issues were introduced in new tests for the certification or recertification of physicians;
- In 2012, "Guidelines in chronic pain management" were adopted by the Board Committee on Guidelines/Ministry of Health (Decree of the Ministry of Health # 01-249 22.08 2012) (http://www.moh.gov.ge/files/01_GEO/jann_sistema/gaidlaini/gaidlain-protokol/117.pdf)
- There are no new barriers to opioid availability, but several very important factors still remain: lack of knowledge/ awareness; problems with legal definitions and terminology; limited number of days where opioids may be dispensed from the police station (though MOLHSA is actively working on replacement of pharmacies from police stations to medical facilities).

Developments/opportunities/barriers relating to the affordability of essential medications:

The national program ensures that the population has access to essential medications; therefore, patients do not have to pay. From 2011, the same program also covers the needs of opioid analgesics for non-cancer patients (prior to that it only covered the needs of oncological patients).

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There have been several initiatives undertaken to liberalise regulations for the legal (medical) use of opioids.

Initiatives to promote attitudinal change in relation to 'opiophobia':

Almost all educational and advocacy work performed between 2008 and 2011 was about raising awareness about unreasonable "opiophobia". A project was prepared by GNAPC with the aim to refine the definitions and remove stigmatising terminology from the Law regulating the legal use of opioids.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

- There exists a State program for home-based palliative care for patients - opioids are free of charge for ambulatory patients with chronic illness in Georgia.

Initiatives that consider access to essential medication as a legal and human right:

- A special project was undertaken in Georgia (2009-2010): "Identifying obstacles to the fundamental human right to be free from pain and improving access to essential medicines". Some lectures and training have also been performed in this area;
- The projects "Stop torture in a Health Care" and "No Pain in our Families" have been actively promoted in Georgia to increase public awareness about the right to access pain medication. A general awareness booklet was published by OSGF in 2012.

A special project was undertaken in Georgia (2009-2010): "Identifying obstacles to the fundamental human right to be free from pain and improving access to essential medicines". Some lectures and training have also been performed in this area

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- Three policy workshops and six "Listenings" dedicated to the development of palliative care were organized between 2005-2010 by the Healthcare and Social Issues Committee of the Parliament of Georgia;
- Policy recommendations on the development of palliative care were signed by international experts J. Stjernswärd and F. Ferris and accepted by the Georgian Parliament (http://www.parliament.ge/files/619_8111_657149_prog_en.doc);
- The position of Coordinator of the National Palliative Care Program (and his Office) was established at the Healthcare and Social Issues Committee at the Parliament of Georgia (Head of the Office – Professor Dimitri Kordzaia) (http://www.parliament.ge/index.php?lang_id=GEO&sec_id=619);
- The portal of palliative care was opened on the website of Parliament of Georgia (http://www.parliament.ge/index.php?lang_id=GEO&sec_id=619);
- In April 2007, the Parliament of Georgia approved amendments to four Laws of Georgia: Law of Healthcare; Law of medical activity; Law of patient's rights; Law concerning narcotics, psychotropic materials, precursors and narcological aids. According to these changes to the Law, the definition of palliative care (as defined by WHO) was accepted ("Law of Healthcare" and "Law of Patient's Rights"); pain relief for terminally-ill patients was recognized as absolutely necessary ("Law of Healthcare"); palliative care was recognized as a necessary component of continuous medical aid to be provided to the patient throughout the illness trajectory ("Law of Healthcare" and "Law of medical activity"); the government accepts the obligation to provide patients with the required amount and forms of opioids as specified by international standards ("Law concerning narcotics and psychotropic materials"). The Ministry of Labor, Health and Social Affairs was obliged to create and sign the normative order "Instruction of Palliative Care for Chronic Incurable Patients" (the President of Georgia signed these amendments in May 2007): (http://www.parliament.ge/index.php?kan_kat_id=13&sec_id=69&lang_id=GEO&kan_id=&kan_text=&kan_from=&kan_to=&kan_num=&Search=%E1%83%AB%E1%83%98%E1%83%94%E1%83%91%E1%83%90);
- On July 10th 2008, the Minister of Labor, Health and Social Affairs signed the normative order changing the rules of opioid prescription;
- In July 2010, the Minister of Labor, Health and Social Affairs signed the normative order changing opioid prescription-forms and liberating opioid prescription;

The impact of these policy changes and ways in which they have been important:

These changes prepared the basis for: the importation of oral morphine and liberalization of opioid prescription; reducing the impact of "opiophobia" among healthcare professionals; improvement in the quality of pain management (and consequently the quality of life of patients); step-by-step increase of financing of palliative care programs throughout the country;

Development of a national palliative care consensus:

- The Georgian government now recognises that the palliative care network must cover the entire country and all the population;
- "The Instruction of Palliative Care for Chronic Incurable Patients" (approved by the Decree of MOLHSA) achieved a national consensus on the aims, methodology and standards of providing palliative care;
- In 2011, the national guideline of chronic pain management for primary health care physicians was developed by a number of palliative care experts.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

- The "Implementation of International Standards in Palliative Care System in Georgia" – (financed by OSGF) and "Recommendations of the European Council on Palliative Care" have been translated and published;

- Presentations of EU recommendations have been conducted in Tbilisi, Batumi and Kutaisi;
- On August 1st 2010, the policy round table dedicated to improvements to the Law regulating the legal use of opioids by refining definitions according to international standards and removing terminology which causes stigmatisation, was organized with the participation of members of Parliament, representatives from different structures of MOLHSA, organizations providing palliative care, and the WHO Country Office; at the round table meeting, a documentary describing barriers to pain management was shown and the film was discussed by all participants.

Development of an advocacy framework for integrating palliative care into the health care system:

- There has been broad acceptance of the national model of incorporation of palliative care into the healthcare system by the Healthcare Committee of the Parliament of Georgia;
- Implementation of the National Program of Palliative Care;
- There has been a slow (but regular) increase of funding for palliative care programs by the Georgian government.

Strategies to improve political awareness and government recognition of palliative care:

- There have been meetings between government officials and international palliative care experts;
- The provision of continuous information by the Office of the National Coordinator in Palliative Care (established at the Healthcare and Social Issues Committee of the Parliament of Georgia);
- The First Lady of Georgia has given TV and radio interviews dedicated to the importance of palliative care;
- The individual work of people devoted to the development of palliative care in Georgia (for example, the International Pain and Policy Fellow, the National Coordinator in Palliative Care, policymakers and government members, holders of international professional certificates, etc.);
- The annual celebration of "World Hospice and Palliative Care Day" since 2007 and related awareness campaigns (events, concerts, marches, etc).

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

- The Georgian government has financed palliative care services in a "crescendo manner" since 2004. These services are provided by NGOs, governmental and private/voluntary palliative care organisations;
- In 2007, the project "Development of Home Care Services in Georgia" (financed by "CORDAID") provided home-based palliative care for (socially unprotected) cancer and non-cancer patients. A multidisciplinary team from CPC provided medical and psycho-social support for patients (who received a minimal package of essential medications);
- In 2007, the project "Palliative Care Development in Georgia" (financed by "CORDAID") within the palliative care department of CPC resulted in the number of beds being increased to 20, the centre being fully renovated and an improvement in service provision;
- Since 2008, the Global Fund's program of palliative care services for HIV/AIDS patients has been implemented by GNAPC, CPC, and NCC and this has resulted in increased coverage; The Global Fund HIV/AIDS program finances: three beds in Tbilisi Hospice for HIV/AIDS patients; two beds in Batumi Hospice for HIV/AIDS patients (located in Batumi Hospital); two beds in Zugdidi Hospice for HIV/AIDS patients (located in the Infectious Diseases Hospital); two beds in Kutaisi Hospice for HIV/AIDS patients (located in the Infectious Diseases Hospital); four mobile teams providing home-based palliative care for HIV/AIDS patients in Tbilisi, Batumi, Zugdidi, and Kutaisi. Since 2012, the Georgian Government has covered the costs of care for HIV/AIDS inpatients.
- The Government of Adjara Autonomous Republic finances: 1000 bed days (100 patients - 10 days/per patient) in the palliative care unit at Batumi Cancer Centre; a mobile team providing home-based palliative care in Batumi; five supporting groups (doctors and nurses) in five municipalities of Adjara (one group per each municipality);

Involvement with the European Union in relation to hospice and palliative care initiatives:

Georgia is a member of the European Council (but not the European Union). Georgia adopted the "Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care" proposed by the Council of Europe in 2003.

Development of initiatives framing palliative care as a 'human right':

Within the "Law of Healthcare" and "Law of medical activity", palliative care is recognized as a necessary component of continuous medical aid to be provided to the patient throughout the illness trajectory. The definition of palliative care was incorporated into the "Law of Patient's Rights" and the concept of pain relief as an essential "human right" has been promoted during round table discussions, training and education, etc.

General legislation relating to palliative care:

See above.

Published national documents relating to palliative care standards and norms:

See above.

National Plan or Strategy of Palliative Care:

In 2009, the Georgian National Program for Palliative Care (Action Plan – 2011-2015) was developed and in July 2010, it was approved by the Healthcare and Social Issues Committee of Parliament of Georgia; (www.palliativecare.org.ge)

National Cancer Control Strategy:

- The National Cancer Control Strategy has been developed and presented at the Academy of Science of Georgia and submitted for further discussion to the Health Care Committee of the Parliament of Georgia (it includes prevention, diagnostics, treatment and palliative care relating to cancer pathology);
- The National Cancer Control Strategy was developed in collaboration with WHO experts;

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy and palliative care has been included in this strategy since 2008.

National Primary Health Care Strategy:

There is a National Primary Health Care Strategy and palliative care is included in this strategy. Primary care services have to provide the basics of palliative care and quality pain management to patients in a "stable condition".

Designated policy maker for the delivery of palliative care services:

There is no designated policy maker for the delivery of palliative care services.

Department of Health specific responsibility for the delivery of palliative care services:

The Department of Health does not have specific responsibility for the delivery of palliative care services. There is a specific State program, which covers 70% of the cost of inpatient palliative care and 100% of the cost of home care.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- There are special regulations for the prescription of opioids and palliative care activists are involved in the further liberalization of opioid legislation for patients with chronic pain (the draft regulation is ready);
- Pain guidelines are currently in progress: special guidelines have been prepared for chronic pain management for primary healthcare physicians (and guidelines for the patient/family) and this document has been submitted to the Ministry of Health for evaluation and approval;
- Chronic pain management issues have been introduced into all medical residential programs.

Funding of palliative care services:

- For palliative care consultation and hospitalisation, the State program provides 70% of funding; the patient provides 30% of funding;
- The State program provides 100% funding for home-based palliative care services;
- For palliative care medication, full payment is required from the patient (except for hospitalised patients or patients receiving home-based palliative care services);
- The charitable foundation "SOCO" has provided financial support for the development of home-based palliative care services in Georgia and for the palliative care "Association Humanists' Union" (2004);
- The Georgian National Scientific Foundation funded a research grant in palliative care and pain management (2009);
- The National Cancer Centre of Georgia is initiating fundraising activities for an international foundation to assist with the development of palliative care in Georgia.

There has been good advocacy and political support. The Georgian National Program for Palliative Care Action Plan (2011-2015) was approved by the Healthcare and Social Issues Committee of Parliament of Georgia in 2010

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

- There has been a periodical demonstration of palliative care video clips on Georgian TV;
- The Report of Jan Stjernsward (WHO and OSI International expert) – “Georgian National Palliative Care Program” was published and distributed among health-care professionals and policymakers. The report was disseminated in both English and Georgian Languages; its electronic version is presented on the website of GNAPC and Parliament of Georgia (http://www.palliativecare.org.ge/cms-images/jan_stjernsward_report_english.pdf) (http://www.parliament.ge/files/619_8111_336972_Paliativi-Eng.pdf);
- The project “Media – Support to Palliative Care Development in Georgia” was implemented and a competition for the best ten publications on palliative care in the press-media was organized;
- Annual meetings dedicated to international “World Hospice and Palliative Care Day” have been conducted. For the organization of “World Hospice and Palliative Care Day” (2010), GNAPC received a special grant from Help the Hospices. A meeting was organized between a delegation from Ukraine - representatives of Verkhovna Rada, Ministries, NGOs and the community - with the First Lady of Georgia and the Health Care and Social Issues Committee of the Parliament of Georgia (the delegation was invited by CPC). The meeting was dedicated to the mutual exchange of experiences in the development of palliative care in Ukraine and Georgia (an agreement was signed by the deputy-speaker of the Parliament of Georgia). A special presentation “Palliative Care Development in Georgia – Juridical, Organizational, Educational and Medical Issues” was prepared by the office of the National Palliative Care Program Coordinator; Dimitri Kordzaia delivered this presentation/lecture in Ukrainian, Latvian, Belarusian, Armenian, and Azerbaijan languages (in the Armenian and Azerbaijan languages, the presentations were conducted within the framework of official programs relating to the visit of the First Lady of Georgia). (http://www.parliament.ge/index.php?lang_id=GEO&sec_id=302&info_id=18144.) (<http://www.osgf.ge/?i=29&l=1&i2=1044&y=2008&p=4>.)

Major public discussion, debate or controversy about hospice and palliative care:

There have been more than ten TV broadcasts of specially prepared discussions about hospice and palliative care.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

In 2008, “The Role of Media in Palliative Care development” (financed by OSGF) examined the way in which the media provided information about the provision of palliative care services in Georgia.

Hospice or palliative care ‘success’ stories:

- In 2004, the first home-based palliative care team (Hospice at Home) was developed by the “Association Humanist’s Union” (currently GNAPC); this team continued to function successfully until April 2011 when it joined the palliative care services at the National Cancer Centre under the leadership of Dr. Tamari Rukhadze. The Centre provides multidisciplinary palliative care for both inpatients and outpatients (in the hospital and at home). The palliative care services at the National Cancer Centre, together with its branches in four regions of Georgia provide palliative care annually for about 1,000 patients. At the same time, the centre established the Academy of Palliative Care which serves as an international educational-research institution for palliative care: medical professionals from Georgia, Tajikistan and Kyrgyzstan have undertaken education-training initiatives at the Centre;
- CPC is one of the pioneers of palliative care in Georgia and as an institution still retains a leading position in the development of the quality and quantity of palliative care services and awareness of palliative care amongst both medical professionals and general society. Rema Gvamichava, Ioseb Abesadze, Pati Dzotsenidze, Mikheil Shavdia, and Giorgi Metivishvil provide lectures and presentations about the benefits and possibilities of palliative care at a variety of events and conferences, as well as interviews with the Georgian media. These activities are gradually beginning to change awareness about palliative care in the country and improve the availability of palliative care services for patients/families. As one of the leaders in the establishment and development of palliative care in Georgia, CPC’s responsibility includes the management of State programs in palliative care which covers 70% of costs and is therefore extremely important for patients/families. The State program has been working since 2004 and there was no interruption until January 2011 when it was suddenly stopped. Responsible persons from the Ministry of Health were unable to provide a clear answer as to why the program had been interrupted, and during this period the number of patients receiving care in CPC and National Cancer Centre Palliative Care Units was decreased to 1 to 2 patients per unit. CPC (Dr Ioseb Abesadze and other physicians, as well as colleagues from National Cancer Centre) initiated a TV interview about this problem with one of the most popular TV channels; following the interview, the problem was resolved instantly;
- The Nuns Mercy Centre Hospice, Monastery of Peristvaleba, Tbilisi, Georgia is an organization established by the Transfiguration Convent in 2003 that provides adult and paediatric inpatient and home-based palliative care to the residents of Tbilisi. The hospice admits only women, and many of their patients are nuns. The priority of the Mercy Centre is to take care of vulnerable families, and provide support for those most in need (usually very poor patients who have extensive problems).

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is no information available at this time.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

- Changes in legislative-normative basis and initiatives;
- Increasing the coverage of regions with palliative care services;
- Increase the country quota and consumption of morphine;
- Education in palliative care (teaching/training).

Most significant issues facing hospice and palliative care in the next three years:

- Organizational and methodological support for the development of palliative care in Georgia;
- Lobbying and obtaining of support from society;
- Research activity.

Implications for palliative care relating to the current economic crisis:

Restrictions in developing new palliative care services in different regions of Georgia: it can also impact on the post-graduate education of physicians and the availability of different forms of essential medicines.

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Germany¹

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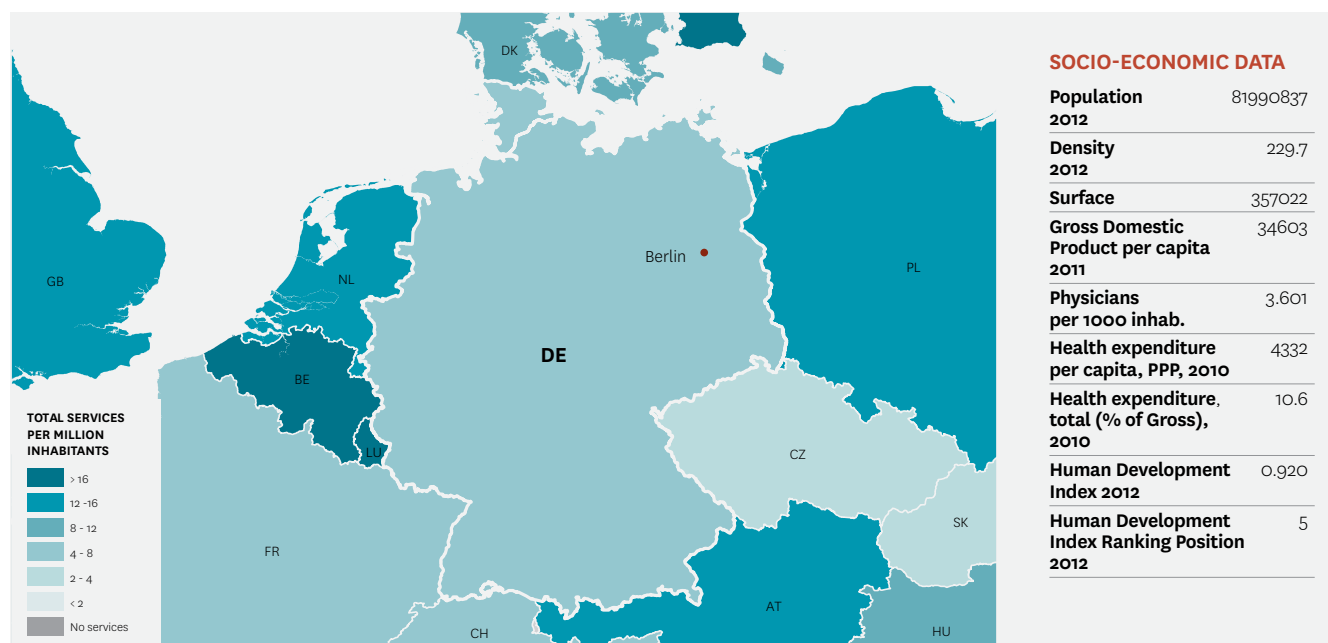
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|--|--|
| Volunteer hospice team | 1244 |
| Hospital palliative care support team | available, but no. not known |
| Home palliative care support team | 180 |
| Mixed palliative care support team | included in the no. of services mentioned under Ref. 2 and 3 |
| Palliative care units in tertiary hospitals | 241 (1843) |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 179 (1729) |
| Day hospice/day care centre | 0 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- German Directory of Hospice and Palliative Care (Wegweiser Hospiz und Palliativmedizin).
- Database as of July 2011; obtained from the team that is responsible for the data collection, particularly Mr. Josef Ross; description of hospice and palliative care services in Germany in: Jaspers B. The Organisation of Palliative Care in Germany. In: Ahmedzai S, Gómez-Batiste X, Engels Y, Hasselaar J, Jaspers B, Leppert W, Menten J, Mollard JM, Vissers K (eds.) Assessing Organisations to Improve Palliative Care in Europe. Vantilt Publishers, Nijmegen 2010: 153-180; ISBN 978-94-91024-01-6.
- Personal information (Heiner Melching, executive director of the German Association of Palliative Medicine).

Additional comments:

- In Germany, volunteer hospice teams don't have hospice beds at their disposal (they are outpatient services); they may be part of the comprehensive services at an inpatient hospice or palliative care unit at which beds are available, they also may be located independent from inpatient services (through cooperation contracts with inpatient services).
- Home palliative care support teams (Adults): There are no valid data available; but it is known that these services are available in many hospitals, linked to a palliative care or pain clinic. Not all of them include a nurse; some include a nurse trained in palliative care and some a nurse trained in pain therapy; additionally, there are also so-called "ambulanter Palliativdienst" for adults, fulfilling the above listed criteria, but their number is not known.
- Palliative care units in non-tertiary hospitals are not available in Germany, even though an increasing number of care homes provide trained nurses and doctors for the delivery of palliative care to their residents/patients.
- Day care provision is very rare in Germany.

Palliative care services for children:

- There are 97 paediatric volunteer hospice teams, 26 paediatric home palliative care support teams, one paediatric palliative care unit in a tertiary hospitals (eight beds), ten paediatric inpatient hospices (108 beds) and two adolescent hospices with eight beds (two further inpatient children's hospices are planned).
- The paediatric palliative care home teams are mainly based in a large hospital.
- There is a very active group of home care teams meeting at least twice a year; eleven teams have a contract with the insurance companies (15 others are in a negotiation with the insurance companies).

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|------------------|--|
| 1999-2005 | Round table meetings and discussions about palliative care 1983: The Deutsche Krebshilfe (German Cancer Aid) funds the first German palliative care unit at the University of Cologne. |
| 1992 | The umbrella movement for the hospice organization is founded (The Federal Hospice Working Group and its Länder Working Groups). |
| 1994 | The German Association for Palliative Medicine is founded. |
| 1996 | The German Ministry of Health initiates a meeting of physicians from PCUs to define a core instrument to be recommended for use in the inpatient units, and to enable the evaluation of the concepts and procedures used in the different units. |
| 2002 | The Federal Hospice Working Group and its Länder Working Groups begins a German-wide statistical project collecting data on patients in hospice services, where are they being cared for, disease and place of death, and the work tasks of volunteers. |
| 2003 | New post-graduate training regulations are passed by the German Medical Association; palliative medicine can now be chosen as a sub-speciality. |
| 2004 | The model project "pain-free hospital" commences, with five participating hospitals. |
| 2004 | The Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organisation of palliative care) is translated into German and a printed version distributed to interested persons (members of the German Association for Palliative Medicine, journalists, participants of the palliative care courses at the Centre for Palliative Medicine, University of Bonn, Malteser Hospital, Bonn). |

EAPC Palliative Care Euro-Barometer 2005

More palliative care units have been established, and there have been an increasing number of specialist home care services since 2009. There is increasing interest in providing palliative care for nursing home residents

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- Federal law stating that patients have a right for specialist palliative care at home introduced in 2009; since then an increasing number of palliative home care services and networks have been established
- A new law introducing mandatory palliative care training for medical students in 2009, so that all medical students wanting to enter the final exams have to show a certificate of such training
- New law that specialist palliative home care services or inpatient hospices may stock opioids, and may include opioids left over from deceased patients into their own stocks and reuse them for other patients.
- New law that specialist palliative home care physicians may dispense opioids for a patient during out-of-office hours, if near on-call pharmacy does not have the appropriate medication available, (2012)
- Increasing interest in hospice and palliative care; for example as a media focus week on State television in November 2012, with more than 40 TV films, shows, etc around death and dying.
- Charter for the severely ill or dying released in 2011, carried by more than 50 institutions, including three governments of federal states.

Overall progress in hospice and palliative care:

Hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: More palliative care units have been established, and there are now more than 400 inpatient palliative care units and inpatient hospices. Inpatient palliative care units and consultation services can get reimbursed by the German DRG system with a specific OPS (Operational procedure code) 9-892.X, if certain criteria are fulfilled. For patients treated longer than six days and with more than six hours per week of specific treatment (including talks with patient and care givers) reimbursement is 1300 Euros in addition to the DRG sum. With this OPS consultation, services can cover their costs, though it is not enough for inpatient units who may struggle with reimbursement rates in the DRG system. Many palliative care units are reimbursed with daily flat rates which (apart from psychiatry day clinics who have a similar prerogative) is the only exemption from the DRG in Germany. Further refinement of the OPS is under way and is expected to result in a second OPS code for inpatient palliative care, which may then lead to more realistic reimbursement for inpatient units that can cover the full costs.
- Nursing homes: There is increasing interest in providing palliative care for nursing home residents. The change in legislation in 2009 (see above, right for specialist palliative care at home) also applies to nursing home residents, for whom the nursing home is considered their home, and who thus have a right for specialist palliative care. Nursing homes could collaborate with home care teams which could provide palliative care for the residents. However, most nursing homes do not use this option and try to provide palliative care themselves. There are a large number of model projects for palliative care in nursing homes, with different content and quality. A framework programme for the Ministry of Health of Northrhine Westfalia has been prepared which is currently under internal revision in the Ministry; the lack of cooperation between nursing homes and specialist palliative care services is striking.
- Residential homes for the elderly: There is little differentiation between residential homes and nursing homes in Germany. The statements above therefore also are applicable for residential homes. Residential homes as well as nursing homes have no physicians among their staff, so the medical care is delivered by GPs. Nurses for the elderly may have two or three years of training, but often the bulk of the nursing care is delivered by nurse assistants who have little training.
- Other community settings: As above, patients have a right to specialist palliative home care since 2009, and an increasing number of specialist home care services have been established since then. There is also increasing interest among family medicine doctors and GPs to learn about and provide palliative care, and an increasing acceptance for the palliative care approach. Most of this is focussed on cancer patients, and non-cancer patients may find it more difficult to access palliative care. Nursing services may offer palliative care, though often with little reimbursement.

Expansion from a focus on cancer patients to address the needs of ‘non-cancer’ patients:

There is little communication between HIV/AIDS and palliative care. TB is not an issue in Germany (very low patient numbers). There is an increasing effort to make palliative care accessible for patients with heart, lung and kidney disease, but the vast majority of patients in the specialist services still are cancer patients. However, the new German task force on ethics in cardiology has included a palliative care specialist, and there has been a slight but continuous increase in the number of non-cancer patients in services in Bonn. There are an increasing number of specialists from other disciplines such as geriatrics, intensive care, internal medicine etc, that attend palliative care courses, and who wish to implement palliative care in their own work area.

Perceived barriers to the development of hospice and palliative care:

- No uniform regulations because of the federal system with 16 federal states, 18 medical boards and 18 sickness fund physicians associations.
- No consensus about general and specialist palliative care: what are the boundaries, how do they collaborate and build up on each other etc?
- No national palliative care strategy.

Perceived opportunities for the development of hospice and palliative care:

- Broad consensus in the community about the importance of palliative care, as evident from the support to legislation changes and support for the Charter for the severely ill and dying.
- Changes in legislation in the last three years that provide a basis for financially viable palliative care services for inpatient and outpatients.
- Growing expertise and capacity with more than eight palliative care professorships.

Other issues relevant to the development of hospice and palliative care:

- Media theme week on national TV on death and dying in November 2012, with a number of palliative care and hospice services and specialists presented in different roles.
- A recent cinema film (Halt auf freier Strecke = ‘Stop outside the station’), describing the life of a patient with brain cancer from diagnosis to death. A real palliative care physician from Berlin played a major part (herself) in the film.

Palliative care research capacity:

- Research centers: Universities (Department of Palliative Medicine) of Aachen, Bonn, Cologne, Erlangen, Freiburg, Goettingen, Jena, Mainz, Munich, Witten-Herdecke/Datteln with extensive research teams.
- Websites: Aachen: <http://www.ukaachen.de/content/folder/3669960>; Bonn <http://www.ukb.uni-bonn.de/quick2web/internet/internet.nsf/vwUNIDLook-up/05F2A0B515A510BC12578110050053F>; Cologne <http://palliativzentrum.uk-koeln.de/zentrum-palliativmedizin/station>; Erlangen: <http://www.palliativmedizin-erlangen.de/>; Freiburg: <http://www.uniklinik-freiburg.de/palliativmedizin/live/index.html>; Goettingen: <http://www.palliativmedizin.uni-goettingen.de/about/index.php>; Jena: <http://www.kim2.uniklinikum-jena.de/KIM+II/Palliativmedizin/Unser+Team.html>; Mainz: <http://www.unimedizin-mainz.de/palliativmedizin/wissenschaftler/uebersicht.html>; Munich: <http://www.izp-muenchen.de/>; Witten-Herdecke: <http://www.uni-wh.de/gesundheitslehre/kinder-schmerztherapie-palliativmedizin/>.
- Researchers: Nils Schneider, University of Hannover; Gabi Lindena, CLARA Berlin (website); Werner Schneider, University of Augsburg
- Nils Schneider: <http://www.mh-hannover.de/nschneider.html>; Gabi Lindena: www.hope-clara.de; Werner Schneider: <http://www.philso.uni-augsburg.de/lehrstuehle/soziologie/sozio3/mitarbeiter/schneider/>

Palliative care collaboration:

- Twinning: There is no information available at this time
- Other relationships: EU-projects ATOME; IMPACT; OPCAREg etc.
- ATOME: <http://www.atome-project.eu/> IMPACT: <http://www.impactpalliative-care.eu/Default.aspx> OPCAREg: <http://www.opcareg.eu/>.
- Pioneers: The pioneer phase was in the early 1980s.
- World initiative: DHPV and DGP; German Palliative Care Foundation.; other national organisations organize events to celebrate World Hospice and Palliative Care Day.

Worldwide palliative care alliance level of development:

4B (Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision).

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- German Association for Palliative Medicine (Deutsche Gesellschaft für Palliativmedizin (DGP)), 1994, <http://www.dgpalliativmedizin.de/>, representative.
- German Hospice and Palliative Association (Deutscher Hospiz- und Palliativ-Verband e.V. (DHPV)), 1992, <http://www.dhpv.de/>, representative.

Directory or catalogue of palliative care services:

Printed; Wegweiser Hospiz und Palliativmedizin Deutschland. First edition 1993, since 2009 web-based, <http://www.wegweiser-hospiz-palliativmedizin.de/>. (database, no book)

Congresses, scientific meetings or scientific journals in palliative care:

- Congresses: Congresses of the German Association for Palliative Medicine (biannual) attended by 2,500 to 3,000 participants; Palliativtag (Palliative Care Day) of the German Association for Palliative Medicine (biannual) attended by 1,000 participants.
- Journals: Zeitschrift für Palliativmedizin published six times per year; Leidfaden (Bereavement) published four times per year; Die Hospiz Zeitschrift (not scientific) published four times per year.

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

Change in legislation in 2009 making palliative care training mandatory for medical students.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Training now mandatory.
- Nursing: Not mandatory, many curricula do not consider this adequately.
- Social work: Not mandatory, but there is a professor for social work in palliative care in Munich.
- Other professions: There is a professor for spiritual end-of-life care in Munich.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: Subspecialty for palliative medicine established some time ago. Multi-professional Master course is offered by Dresden International University.
- Nursing: There is a 160 hour course in palliative care which is well acknowledged and which many nurses have undertaken. Multi-professional master course is offered by Dresden International University.
- Social work: There is a curriculum for postgraduate training for other professions from the German Association for Palliative Care. Multi-professional master course is offered by Dresden International University.
- Other professions: As above.

Translation of palliative care documents or other materials:

German translations of the Prague Charter, of the EAPC sedation framework, and the EAPC White paper on standards and norms are available on the EAPC website and the website of the German Association for Palliative Medicine.

Initiatives to develop healthcare professional leadership in palliative care:

- Several new chairs of palliative medicine have been developed, and all offer academic careers for physicians and other professions including “Habilitation” (the German equivalent of PhD, though you have to do rather a lot more than for a PhD).
- A leadership programme in palliative care funded by the Robert Bosch Foundation and led by the University of Cologne together with Kings College in London, Casa Sperantei in Brasov and a Polish University will commence this summer.

Officially recognized medical certification:

- Since 2003 there has been a Palliative Medicine sub-specialty in Germany; physicians from all patient-based specialties are permitted to access.
- Requirements are: experience (knowledge and skills) with patients in need of palliative care (to be gained in the period of continuous education for a patient-based specialisation in a medical discipline; approved specialisation in a medical discipline; 40 hrs basic course in palliative care and; 12 months practical continuous training in a palliative care service, headed by a physician with certification for postgraduate medical training in palliative medicine. If physicians attend a [certified] 120 hour case seminar, the practical training may be shortened accordingly. The German Association for Palliative Care estimate that around 6,000 physicians are certificated in Palliative Medicine.
- A 40 hrs basic course in palliative care was developed in 2008; this a prerequisite for remuneration of GP services in palliative care in some States of Germany and for co-operation with specialised teams in palliative care.

Capacity of palliative care workforce training in Universities and Medical Schools:

- There are 36 medical schools in Germany of which 15 have palliative medicine as a mandatory component (the medical schools of two universities are working as one university unit therefore the number is 36 instead of 37). Ref: Ilse B et al.: Palliativmedizinische Lehre in Deutschland. Planungen der Fakultäten zum zukünftigen Querschnittsfach submitted GMS Z med Ausbild 2012 (Survey among medical schools in Germany, response rate: n=35);
- From 2013, palliative care is a mandatory component of tuition and examination in Germany (by law). Currently, nearly all (34) universities provide tuition in palliative medicine to some extent (ref. Laske et al: Undergraduate medical education in Palliative Medicine in Germany (Report of 2009. Z Palliativmed 2010; 11:18-25) is provided in some explicit Palliative Medicine courses, some is integrated in the courses of other specialties.
- There are five full professors, including one chair for paediatric palliative care. There are three “other professors” of palliative care, one of them for paediatric palliative care. There are also three “other professors non-medical”: two in spiritual care and one in social work.

There have been a number of important changes in legislation relating to financially viable palliative care services, mandatory palliative care training for medical students, and the stocking, dispensing and reuse of opioids

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006**Developments/opportunities/barriers relating to the availability of essential medications:**

All available, with a broad scope of opioids and other essential medicines. Minor problems with opioid prescription or dispensing have led to adjustments of the legislation in 2011 and 2012. Scopolamin is not available, but glycopyrrrolat and butylscopolamin are.

Developments/opportunities/barriers relating to the accessibility of essential medications:

- All essential medicines are accessible. There is still a reluctance to prescribe opioids to non-cancer palliative care patients, and there are still physicians with inadequate training, but the situation has improved vastly since 2006
- Opioids may be stocked in inpatient hospices and by specialist palliative home care teams and these services can also take back unused opioids from deceased patients and re-use them for other patients. More recently, physicians were also allowed to dispense small quantities during out-of-office hours if on-duty pharmacies in the vicinity do not have the medicines available.

Developments/opportunities/barriers relating to the affordability of essential medications:

All medicines are covered by health care insurance (mandatory in Germany); patients have to pay only a small fee per prescription (seven Euros per prescription), and cancer patients are exempt from that fee.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

Legislation has removed restrictions.

Initiatives to promote attitudinal change in relation to ‘opiophobia’:

Charter released in 2010 included strong recommendation to use opioids where indicated.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is mandatory health insurance in Germany.

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- Federal law stating that patients have a right for specialist palliative care at home introduced in 2009.
- New law introducing mandatory palliative care training for medical students in 2009, so that all medical students wanting to enter their final exams have to show a certificate of such training.
- New law that specialist palliative home care services or inpatient hospices may stock opioids, and may include opioids left over from deceased patients into their own stocks and reuse them for other patients.
- New law that specialist palliative home care physicians may dispense opioids for a patient during out-of-office hours, if a near on-call pharmacy does not have the appropriate medication available, (2012).

The impact of these policy changes and ways in which they have been important:

The number of specialist services for palliative home care has substantially increased. Palliative care is acknowledged as an academic subject by medical faculties.

Development of a national palliative care consensus:

- The National charter for the care of severely ill or dying patients (Charta zur Betreuung von Schwerstkranken und Sterbenden) was released in 2010, and has been supported by more than 50 institutions, including federal ministries from three States.
- Guidelines for palliative care are being developed by the Drug Commission of the German Medical Board and also by the Association of the Scientific Medical Societies in Germany and will be released in 2013.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

The Charter mentioned above is currently being used as a basis to achieve a national strategy.

Development of an advocacy framework for integrating palliative care into the health care system:

As palliative care is integrated in the national health care system (services and reimbursement structures are available for inpatients and outpatients), such an advocacy framework is not really needed.

Strategies to improve political awareness and government recognition of palliative care:

- Initiation of the Charter by the two professional associations (German Association for Palliative Care and German Hospice Association) and the German Medical Board, released in 2010
- National focus week in the media on death and dying in Nov 2012.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

Special OPS code in the German DRG system for complex palliative care inpatient treatment; reimbursement schemes for palliative specialist home care; reimbursement regulated in German social law for coordinators of volunteer services.

Involvement with the European Union in relation to hospice and palliative care initiatives:

Participation of German researchers in EU-funded research collaboratives (OP-CARE; PRISMA; ATOME; IMPACT; INSUP-C).

Development of initiatives framing palliative care as a 'human right':

- Initiation of the Prague Charter supported by German co-workers in the EAPC task force that has prepared the Charter (German translation available and adopted by the board of the German Palliative Care Association in January 2013).
- In addition, the right for palliative care is a core feature of the German charter.

General legislation relating to palliative care:

The right to access to specialised palliative care whenever needed, at any time and in all situations was introduced in SGB V (Social Security Code; §§ 37 b and 132 d) in 2007. Other new legal regulations include reduction of self-funding of children's hospices from 10 to 5% of total costs (amendment of § 39a Section 1 SGB V), implementation and funding of integrated models of care (§ 140 a-d SGB V) and financially supported leave for family caregivers of patients with nursing care dependency (up to six months covering of social insurance contributions, job guarantee). New regulations for the licensing of physicians 2009 – Palliative Medicine to be mandatory in tuition and examination of medical students (physicians) from 2013 onwards (http://www.gesetze-im-internet.de/_appro_2002/BJNR240500002.html).

Published national documents relating to palliative care standards and norms:

Translation and extensive process of coordination and publishing of the EAPC IMPACT Statement.

National Plan or Strategy of Palliative Care:

There is no information available at this time.

National Cancer Control Strategy:

There is a National Cancer Control Strategy but it does not contain a reference to palliative care provision.

There has been increasing media interest in palliative care and broad consensus in the community about its importance as evident from the support to legislative changes (for example, the Charter for the Severely Ill or Dying in 2011)

National HIV/AIDS Strategy:

There is no information available at this time.

National Primary Health Care Strategy:

There is no information available at this time.

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

- The aim to promote palliative care was written down in the coalition treaty, but there is no particular person in the federal government in charge of palliative care.
- In the States of Germany, the state ministries of either health or social affairs are responsible for palliative care; some have developed frameworks on the delivery of palliative care.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

National Hospice and Palliative Register; website: www.hospiz-palliativ-register.de; Based on HOPE (Hospice and Palliative Care Evaluation), with more than 20,000 patient datasets, multiple publications by the HOPE research group, benchmarking for individual settings, annual prospective survey among settings in Germany (PCU, inpatient hospices, outpatient services).

Opioid legislation/Pain guidelines:

- Opioids: prescription - http://www.gesetze-im-internet.de/btmvv_1998/BJNR008000998.html (particularly § 8); also see Cherny et al. Formulary availability and regulatory barriers to accessibility of opioids for cancer pain in Europe: a report from the ESMO/EAPC Opioid Policy Initiative. *Annals of Oncology* 21:615-626 (2010) (particularly figure 6).
- Acquisition http://www.gesetze-im-internet.de/btmvv_1998/BJNR008000998.html (particularly § 1); also see Cherny et al. Formulary availability and regulatory barriers to accessibility of opioids for cancer pain in Europe: a report from the ESMO/EAPC Opioid Policy Initiative. *Annals of Oncology* 21:615-626 (2010) (particularly figure 8); opioids are generally available.
- Pain guidelines: There is a national guideline on neuropathic pain and a consensus paper of several important institutions and groups on the treatment of tumor pain in adults and children (two different publications). Guidelines on tumor pain, supportive care in palliative care for cancer patients and fast acting fentanyl preparations are in work.

Funding of palliative care services:

- There is no payment required for consultation; payment; is fully covered by statutory and private health insurances
- There is partial payment required for hospitalisation; an extra fee of 10 € per day must be paid.
- There is partial payment required for medications provided at home (none required when in hospital).
- There is funding of chairs in Palliative Medicine at universities by German Cancer Aid and the Vodafone Foundation.

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

- Lots of change - there are 80,000 volunteers in the hospice or palliative care movement in Germany (from a population of 80 million inhabitants); this makes it a big social movement,
- The focus week on death and dying in the media in November 2012,
- Major initiatives that have changed public awareness considerably. For example, hospice goes to school is a project initiated by the German Hospice Association where trained hospice volunteers do project work on loss and death with primary school classes, culminating in a final event with the children and parents. Usually there is a lot of discussions before and during the project week with teachers, parents and relatives which makes the circle of influence of these project weeks much wider than just the children in the classes.

Major public discussion, debate or controversy about hospice and palliative care:

The media focus week in November 2012.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

- There have been a lot of activities; there is the German Hospice day and a huge number of services participating in the World Hospice and Palliative Care Day.
- A German book written by palliative care expert Gian Borasio (Über das Sterben = About dying) has been in the bestseller charts for some time.

Hospice or palliative care 'success' stories:

The charter for severely ill and dying patients, the media focus week in November, the changes in the legislation introducing the right for specialist palliative home care or making palliative care training mandatory for medical students.

Initiatives seeking the legalisation of euthanasia or assisted dying:

- There have been some initiatives, including the ex-senator of internal affairs Roger Kusch who presented a suicide machine in 2008 in the media, and advocated for assisted dying. Dignitas, the Swiss organisation for assisted dying opened a German branch in Hannover, but was not able to start business there. The German Medical Board has revised their guidelines on physicians care at the end of life in 2011, and now states that there is a broad scope of opinions on assisted suicide, but that it is not part of the physician task. The previous version has stated that it is against medical ethics to assist suicide. This met considerable criticism and is still discussed among physicians.
- The German criminal law does not penalize suicide, and in consequence does not penalize assistance with suicide. A recent initiative from the ministry performed with commercial intent, similar to the legislation in Switzerland. However, the draft text also said that physicians may offer assistance when they do this without commercial intent, and again this was criticized heavily (the draft is still under discussion).

There has been lots of change - there are 80,000 volunteers in the hospice or palliative care movement in Germany (from a population of 80 million inhabitants); this makes it a big social movement

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

Service development is expanding quickly, and has reached full coverage in some regions in Germany. Ongoing and continuous growth and an increasing acknowledgement within the academic setting are expected. Political support will continue, and palliative care will slowly expand also to the groups that still have problems in accessing it: prisoners, the disabled, migrants, residents in nursing homes.

Most significant issues facing hospice and palliative care in the next three years:

There are different models of services and reimbursement schemes in the federal states, and one of the major challenges in the future will be to align these different models, consent on common quality indicators and contribute to nationwide quality assurance programmes (which exist, but are only a part of services).

Implications for palliative care relating to the current economic crisis:

There is less funding from industry to palliative care, but this is not a major motor of palliative care development in Germany. As Germany is less wounded by the economic crisis, the implications have not been too hard yet. If the recession gets worse, it is to be expected that palliative care reimbursement, funding and support will diminish. However, palliative care has been proven as a cost-effective alternative for usual end-of-life care. It does cost money, but it also saves as unnecessary hospital stays and futile treatment interventions in the last phase of life are reduced. This might make palliative care even more desirable when the economic situation gets worse.

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Service development is expanding quickly, and has reached full coverage in some regions in Germany. Ongoing and continuous growth and an increasing acknowledgement within the academic setting are expected

Greece¹

KEY CONTACT/NATIONAL ASSOCIATION

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and non-Cancer Patients**
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Information for this country report was provided by
two 'key persons' in the development of palliative
care in Greece.

¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 1 |
| Hospital palliative care support team | 0 |
| Home palliative care support team | 1 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 1 |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 0 |
| Day hospice/day care centre | 2 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Ministry of Health, Hellenic Society for Palliative - Symptomatic Care for Cancer and non-Cancer Patients, 11th Congress of Pain Management and Palliative Care, Samos 2010;
- www.merimna.org;
- www.yyka.gov.gr;
- www.grpalliative.gr (HSPSCCNCP);
- Newsletter of HSPSCCNCP, v.2, p.2-3;
- Newsletter of HSPSCCNCP, v.7, p.2-3;
- Journal iasis, Sep. 2011, p.16-18;
- Hellenic Society of Palliative Symptomatic Care for Cancer and Non Cancer Patients, Newsletter v.15 p.1 12th Congress of Pain Management and Palliative Care, Elounda, Crete, 2011;
- www.regionalpainpalliativecongress2011.gr;
- Ministry of Health /Hellenic Society of Palliative Symptomatic Care for Cancer and non-Cancer Patients, newsletter v.9, p.4-7, International Symposium of World Institute of Pain, Mykonos, Greece 2009.

Additional comments:

- There are no national palliative care units officially established in Greece but 72% are part of the pain centers of Anaesthesia departments and a 24-hours service is offered by pain and palliative care specialists on a voluntary basis; there are 80 volunteer pain services; 57 hospital pain services; 15 home-based pain services; four mixed pain services; two pain services in a tertiary hospital; and eight pain services in day care centres.
- There are no beds for palliative care in any national health hospital in Greece.

Palliative care services for children:

There are six volunteer paediatric pain teams; two paediatric hospital pain teams; four paediatric home pain teams; two paediatric mixed pain teams; two paediatric pain units in tertiary hospitals; and two paediatric pain services in day care centres. There is also one paediatric inpatient pain service.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|-----------|--|
| 1994 | The "Pain Relief and Palliative Care" course begins to be taught as an elective subject at the University of Athens. |
| 1997 | The Hellenic Society of Palliative and Symptomatic Care of Cancer and non-Cancer patients is established. |
| 2000-2005 | With the financial cooperation of the Jenny Karezi foundation a Pain Relief and Palliative Care Unit is opened in the University of Athens in a separate building with a day care unit, an out-patient unit, a research room and a seminar/education area. They organize palliative care seminars for nurses and social workers within the municipality of Athens. |
| 2004 | The Pain Relief and Palliative Care Unit mark the publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organisation of palliative care) by translating and editing the report. |
| 2005 | The principle that Greek doctors are obliged to alleviate pain and offer quality of life through palliative care to terminally ill patients is established for the first time in Greek law. |
| 2006 | The 8th Panhellenic Conference on Regional Anaesthesia, Pain Management and Palliative Care, is held with international participation (Olympia, May 19-21, 2006). |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- The National Plan against Cancer (2011-2013);
- The regulation from December 2007 relating to pain centers;
- The regulation from August 2008 relating to hospices;
- The involvement of the Church in palliative care;
- The cooperation of society and policy makers.

Overall progress in hospice and palliative care:

Hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: There has been development of pain and palliative care centers
- Nursing homes: There is no information available at this time.
- Residential homes: There is no information available at this time.
- Other community settings: There is no information available at this time.

There has been a further development of pain and palliative care centres in Greece where the needs of dementia and HIV/AIDS patients (in addition to cancer patients) are now being addressed

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

The needs of dementia and HIV/AIDS patients are now being addressed.

Perceived barriers to the development of hospice and palliative care:

(i) Opioid legislation (ii) lack of public awareness (iii) opiophobia.

Perceived opportunities for the development of hospice and palliative care:

(i) Government support (ii) education initiatives (iii) change to opioid legislation.

Other issues relevant to the development of hospice and palliative care:

- Education workshops in the field of palliative care;
- National Congresses with international participation;
- Publications and newsletters;
- Campaigns in newspapers and on TV;
- Cooperation with the Ministry of Health on European projects.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- The Hellenic Association of Pain Control and Palliative Care (ΕΛΛΗΝΙΚΗ ΕΤΑΙΡΙΑ ΑΝΑΚΟΥΦΙΣΤΙΚΗΣ – ΠΑΡΗΓΟΡΗΤΙΚΗΣ ΑΓΩΓΗΣ ΚΑΙ ΦΡΟΝΤΙΔΑΣ) was formed in 1997; the association has a website (www.monadaanakoufisis.gr) and is representative of the whole country;
- The Hellenic Society for Palliative - Symptomatic Care for Cancer and non-Cancer Patients (Ελληνική Εταιρεία Παρηγορητικής – Συμπτωματικής Φροντίδας Καρκινοπαθών και μη Ασθενών) was formed in 1997; the association has a website (www.palliative.gr) and is representative of the whole country;

Directory or catalogue of palliative care services:

- www.yyka.gov.gr.
- www.grpalliative.gr.

Congresses, scientific meetings or scientific journals in palliative care:

- A Pediatric Palliative Care Symposium is held bi-annually and is attended by approximately 300 people;
- The Hellenic Society for Palliative - Symptomatic Care for Cancer and non-Cancer Patients organizes *The Panhellenic Congress of Regional Anaesthesia Pain Control & Palliative Care* annually (approximately 300-450 people attend the congress);
- A palliative care newsletter of the Hellenic Society for Palliative - Symptomatic Care for Cancer and non-Cancer Patients is produced every three months.

Palliative care research capacity:

- Research centers: Palliative Care Unit, Radiology Department, School of Medicine, National and Kapodistrian University of Athens; University of Athens, Pain Relief and Palliative Care Center, Anaesthesiology Clinic, Aretaieion Hospital Athens.
- Researchers: Athina Vadalouka, MD, PhD, FIPP, Associate Prof. of Anaesthesia, Pain Management and Palliative Care, University of Athens, Chair of the Mediterranean Section of WIP, ESRA Past President, President of Hellenic Society for Palliative Symptomatic Care for Cancer and non-Cancer Patients; Kyriaki Mystakidou, Associate Professor in Palliative Medicine, Palliative Care Unit, Radiology Dpt., School of Medicine, University of Athens; Irene Panagiotou, MD, PhD, Palliative Care Unit, Radiology Dpt., School of Medicine, University of Athens; Eleni Tsilika, Health Psychologist, Palliative Care Unit, Radiology Dpt., School of Medicine, University of Athens; Efi Parpa, Clinical Psychologist, Palliative Care Unit, Radiology Dpt., School of Medicine, University of Athens; Elizabeth Patiraki, Professor of Nursing Faculty, University of Athens; Danaï Papadatou, Professor of Clinical Psychology, Nursing Faculty, University of Athens.

Palliative care collaboration:

- Collaboration with the ATOME Project; ECEPT; Help the Hospices; EAPC; Hospice Casa Sperantei, Romania.
- Collaboration with “st. Savas” Cancer Hospital of Athens and “Galilee” Home-care Palliative Unit, Holy Metropolis Messogaia and Lavreotiki; a memorandum of collaboration was signed between the Cancer Hospital of Athens and the non-governmental palliative home care team. Patients treated in the hospital are referred to the home palliative care team and there is information exchange about the needs of patients between the two parties. The partnership has been ongoing since 2010;
- A memorandum of collaboration was signed between the Palliative Care Unit, School of Medicine, University of Athens and “Jenny Karezi” Foundation (a non-profit palliative care organization) through patient referrals to the Unit;
- There is also collaboration with the Hellenic Pediatric Palliative Care Association;
- Pioneers in palliative care include: the Hellenic Society for Palliative - Symptomatic Care for Cancer and non-Cancer Patients; Palliative Care Unit, School of Medicine, University of Athens; Merimna; Church of Greece; “Jenny Karezi” Foundation.
- World Hospice and Palliative Care Day initiatives have been undertaken by: the Hellenic Association of Pain Control and Palliative Care; the Hellenic Society of Palliative and Symptomatic Care of Cancer and non-Cancer Patients; the Hellenic Pediatric Palliative Care Association; the “Jenny Karezi” Foundation. All these societies organize scientific meetings and announcements are made in newspapers and the mass media to raise public awareness of palliative care. The Panhellenic Congress of Pain Management and Palliative Care holds a music event and a special issue of the newsletter produced by the Hellenic Society of Palliative and Symptomatic Care of Cancer and non-Cancer Patients is dedicated to World Hospice and Palliative Care Day.

Worldwide palliative care alliance level of development:

3A (Isolated palliative care provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

A Master's degree in palliative care is now available in the Nursing School in the University of Athens.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Elective module in the University of Athens
- Nursing: As above
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: There is no information available at this time.
- Nursing: As above
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Translation of palliative care documents or other materials:

The Hellenic Society for Palliative - Symptomatic Care for Cancer and non-Cancer Patients translates the main topics of the European Journal of Palliative Care into Greek and publishes clinical updates in their newsletter. They also publish the translation of different guidelines (e.g. relating to breakthrough pain) and other documents (for example, EAPC White Papers, etc.).

Initiatives to develop healthcare professional leadership in palliative care:

There are initiatives to develop healthcare professional leadership in palliative care.

Officially recognized medical certification:

- There is no medical specialization for palliative care in Greece and no estimated date for specialist accreditation. The Hellenic Society of Palliative and Symptomatic Care for Cancer and non-Cancer Patients makes every effort to persuade the Greek government to establish an official pain relief and palliative care centre in every hospital;
- Palliative care has been available as an elective module since 1994 in the University of Athens; a Master's degree commenced in the University of Athens, Faculty of Nursing (in cooperation with the School of Medicine) in 2009. The degree, entitled: “Organization and Management of Supportive and Palliative Care in Chronically Ill Patients” lasts four semesters, and consists of a total of 1,200 hours study and 200 hours of clinical training at the Palliative care Unit, Radiology Department, School of Medicine, University of Athens (approximately 20 students have undertaken the degree course);
- The Hellenic Society for Palliative - Symptomatic Care for Cancer and non-Cancer Patients has organized eight seminars in palliative care for doctors between 2000 and 2008; approximately 40 - 50 participants attend each seminar which comprise of 12 hours education and five hours of clinical training;
- The Hellenic Society for Palliative - Symptomatic Care for Cancer and non-Cancer Patients organized a seminar in palliative care nursing in 2012.

Capacity of palliative care workforce training in Universities and Medical Schools:

- There are seven medical schools in Greece: one of them has palliative care as an obligatory component, and six of them have palliative care as an element of other courses (Source: curriculum of Medical School of University of Athens).
- There are two “other professors” (Associate Professors) of palliative medicine and two full professors (non-medical) (one psychologist and one nurse) (Source: www.grammateia.med.uoa.gr).

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

There is no information available at this time.

Developments/opportunities/barriers relating to the accessibility of essential medications:

There is no information available at this time.

Developments/opportunities/barriers relating to the affordability of essential medications:

There is no information available at this time.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to ‘opiophobia’:

There have been initiatives in publications; educational programmes for healthcare professionals and patients; campaigns on TV and in newspapers.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

Access to opioid medication for economically disadvantaged persons is covered by the national health system.

Initiatives that consider access to essential medication as a legal and human right:

No.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

The new legislation on pain centers and hospices.

The impact of these policy changes and ways in which they have been important:

The Greek government has changed its view of palliative care.

Development of a national palliative care consensus:

A national consensus has been achieved through development of palliative care legislation.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

There have been many meetings with stakeholders and policy makers to develop palliative care strategies.

Development of an advocacy framework for integrating palliative care into the health care system:

There is no information available at this time.

Strategies to improve political awareness and government recognition of palliative care:

There have been many meetings between the Hellenic Society for Palliative - Symptomatic Care for Cancer and non-Cancer Patients and healthcare policy makers. During the 2011 National Congress (13th-16th October 2011), a meeting was organized with Professor Irene Higginson and Government representatives to discuss ways to improve palliative care in Greece.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

- The Church has started a home-based palliative care service for cancer patients;
- Donations from society support home-based palliative care services.

Involvement with the European Union in relation to hospice and palliative care initiatives:

ATOME project; PRISMA project.

There have been a number of important legislative changes relating to opioids and pain centres (2007) and hospices (2008); this was due in part to increased collaboration between National Associations and governmental policy makers

Development of initiatives framing palliative care as a 'human right':

There have not been enough initiatives framing palliative care as a 'human right'.

General legislation relating to palliative care:

- Since August 2007, there has been a specific Ministerial Decree referring to the prerequisites for building and organizing hospices in Greece.
- http://www.grpalliative.gr/pdf/Journal/parhsya_issue8.pdf.

Published national documents relating to palliative care standards and norms:

There is no information available at this time.

National Plan or Strategy of Palliative Care:

There is no information available at this time.

National Cancer Control Strategy:

- In the National Plan for Public Health (2008-2012) the Ministry of Health includes the development of pain clinics, palliative care units and hospices within the section on cancer;
- There is a National Cancer Control Strategy in process at the Ministry of Health (<http://www.anti-cancer.gr/pages/7.>).

National HIV/AIDS Strategy:

The National Center of Control and Prevention of Diseases is responsible for the National HIV/AIDS Strategy (but it does not contain an explicit reference to palliative care provision); <http://www.yyka.gov.gr/articles/health/domes-kai-draseis-gia-thn-ygeia/ethnika-sxedia-drashs/95-ethnika-sxedia-drashs>.

National Primary Health Care Strategy:

There is a National Primary Health Care Strategy (but it does not contain an explicit reference to palliative care provision).

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

There is no information available at this time.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- A special prescription must be signed by a general practitioner, or specialty or hospital physician. Strong opioids are only available in the pharmacy or in the hospital.
- Pain guidelines: online version (www.grpalliative.gr.) There are also pain guidelines in process: National Guidelines on Neuropathic Pain (Malignant - non Malignant) by the Hellenic Society for Palliative Symptomatic Care for Cancer and non-Cancer Patients.

Funding of palliative care services:

There is no payment required for palliative care consultation, hospitalisation or medication (in National Health Care Hospitals for cancer patients).

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

There has been a change in public awareness/perception of hospice and palliative care through media campaigns and increased government recognition.

Major public discussion, debate or controversy about hospice and palliative care:

There has been a discussion about hospice and palliative care in the Greek Parliament, and a public discussion takes place annually during the celebration of World Hospice and Palliative Care Day.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

Different media initiatives have taken place to broaden awareness and understanding of hospice and palliative care.

Hospice or palliative care 'success' stories:

Newspapers have published numerous stories of patients who were supported by palliative care services.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is no information available at this time.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

To improve quality of life and patient satisfaction.

Most significant issues facing hospice and palliative care in the next three years:

To provide home-based care for all patients who need it; to educate people about palliative care; to organize multidisciplinary palliative care teams; to persuade the Government to change its philosophy towards opioid availability and support efforts to improve palliative care in Greece.

Implications for palliative care relating to the current economic crisis:

Save money from reduced hospitalizations.

The Church has become more involved in palliative care and there has been increased awareness and recognition about palliative care within society. A National Plan against Cancer (2011-2013) has been produced

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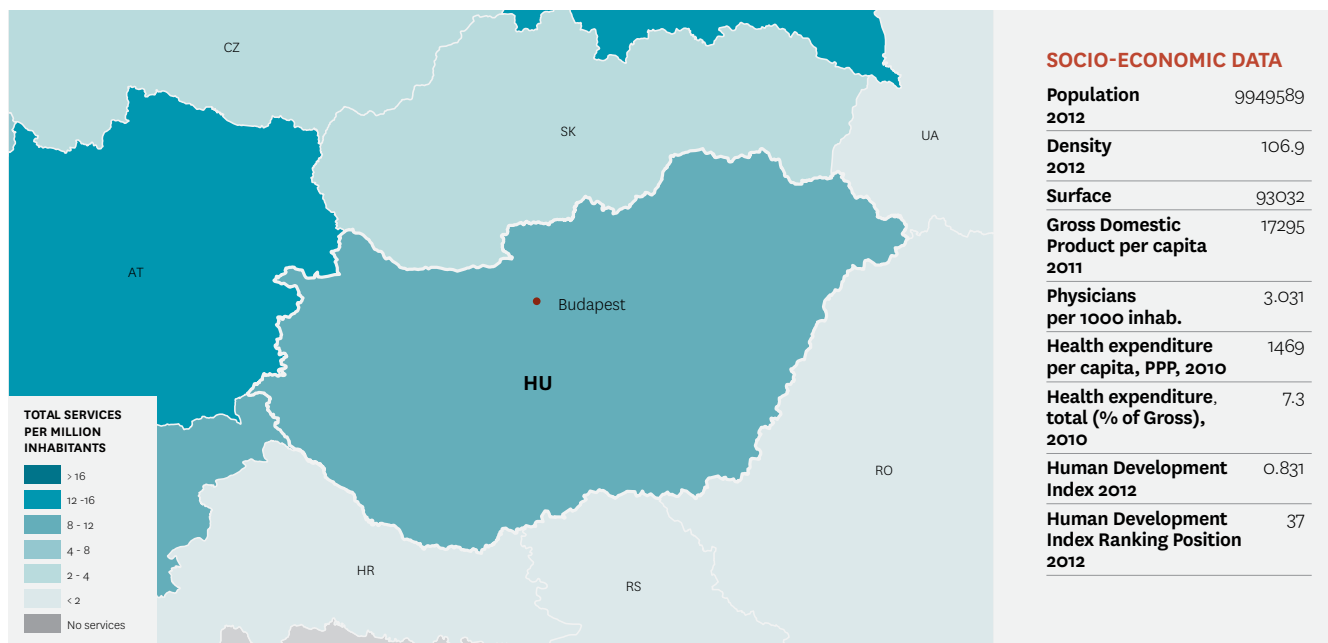
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 3 |
| Home palliative care support team | 69 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 10 (162) |
| Palliative care units in non-tertiary hospitals | 2 (15) |
| Inpatient hospice | 1 (10) |
| Day hospice/day care centre | 2 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Dr. Katalin Hegedus - Katalin Munk: Annual report of the Hungarian Hospice Palliative Care Association, 2010: <http://www.hospice.hu/hospice-jelentesek/456>.
- Dr. Katalin Hegedus - Katalin Munk: Annual report of the Hungarian Hospice Palliative Care Association, 2011: <http://www.hospice.hu/hospice-jelentesek/563>
- Gábor Benyó, www.szememfenye.hu/
- Agnes Csikos MD, PhD. www.pecshospice.hu

Additional comments:

There is no additional information available at this time.

Palliative care services for children:

There are two paediatric inpatient hospices (nine beds); both hospices opened in 2011.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|---------|---|
| 1991 | The Hungarian hospice movement is founded. |
| 1994-95 | Hospice teams begin to form with the help of the Soros Foundation. |
| 1994 | Oral morphine, tramadol and dihydrocodeine are available free of charge to cancer patients. |
| 1997 | Hungarian Health Law declares the human right of palliative care, and defines hospice care. |
| 2000 | Regional and nationwide campaigns against pain are organized by the Cancer League and Hungarian Hospice Palliative Association. |
| 2002 | A detailed palliative care guideline is launched which deals not only with professional but also constitutional and financial aspects of palliative care. |
| 2004 | The Health Ministry launches the hospice minimum condition which provides official licences. |
| 2004 | There is a new hospice financing system which takes the whole hospice team into account. |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- The quantitative expansion of hospice/palliative care services due to financial support provided by the National Health Insurance Fund.
- Establishment of the Department of Hospice-Palliative Care at Pecs University Medical School Institute of Family Medicine.

Overall progress in hospice and palliative care:

- Hospice and palliative care has improved.
- Home-based palliative care services have become more widely available across the country.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: There has been limited development;
- Nursing homes: There has been no development (reduced from six to two);
- Residential homes for the elderly: There has been no development (from 0 to 0);
- Other community settings: There has been some development: the number of home hospice care services has increased to 69 and the number of paediatric hospices has increased to two; however, hospital palliative care support teams have been reduced from four to three.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

The majority of palliative care is provided to cancer patients, although patients with autoimmune disease, ALS or HIV/AIDS are now also covered.

Perceived barriers to the development of hospice and palliative care:

- Lack of appropriate knowledge about palliative care and pain management amongst physicians;
- Lack of obligatory palliative care training in medical schools and postgraduate physician training;
- No palliative care units within university clinics;
- Problems relating to the quality of care provided (lack of genuine multi-disciplinarity).

Perceived opportunities for the development of hospice and palliative care:

- Specifying professional criteria, competence and relationships;
- Strengthening professional recognition of palliative care;
- Development of management and fund-raising activities;
- Development of palliative care licence exam for physicians.

Other issues relevant to the development of hospice and palliative care:

- Basic and professional training with a high number of attendants;
- Social recognition and public awareness of palliative care has improved;
- Significant international recognition (the 10th EAPC Congress in 2007 was held in Budapest).

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

The Hungarian Hospice Palliative Association (Magyar Hospice-Palliatív Egyesület) was formed in 1995; the association has a website (www.hospice.hu), and is representative of the whole country.

Directory or catalogue of palliative care services:

- There is a printed catalogue of palliative care services: *Ad idősgondozás kézikönyve* (The manual of care of elderly); the first edition was printed in 2007 and the latest edition in 2011;
- There is an online catalogue of palliative care services: <http://www.hospice.hu/hospice-ok/>; the first edition was posted online in 2005 and the latest edition in 2011.

Congresses, scientific meetings or scientific journals in palliative care:

- Congresses of the Hungarian Hospice Palliative Association are held every two years, and are attended by 300-350 participants; there are also many congresses at both the local and regional levels.
- The journal *Kharon Thanatologiai Szemle* is published four times each year (www.kharon.hu).

Palliative care research capacity:

- Research centers include: Semmelweis University Budapest, Faculty of Medicine, Institute of Behavioural Sciences (Dr. Katalin Hegedus, hegkati@net.sote.hu); University of Pécs, Faculty of Medicine, Institute of Family Medicine, Department of Hospice-Palliative Care (Dr. Ágnes Csikos, agnes.csikoska@gmail.com); University of Szeged, Faculty of Medicine, Institute of Behavioural Sciences (Dr. Katalin Barabas, bar@nepsy.szote.u-szeged.hu);
- Other researchers include: Dr. Ágnes Biró, eszter.biro@hospicehaz.hu.

Home-based palliative care services have become more widely available across the country and the number of paediatric hospices has increased. Patients with autoimmune disease, ALS or HIV/AIDS are now also eligible to receive palliative care

Palliative care collaboration:

- There is twinning with St. Christopher's Hospice, London UK;
- There is palliative care collaboration with: San Diego Hospice, Institute for Palliative Medicine, San Diego, CA, USA; SUMMA Health System, Akron, OH, USA; Hospice Casa Sperantei, Brasov, Romania; Palliative Care Centre Unna, Katharinen-Hospital, Unna, Germany (research, educational and travelling scholarship collaboration);
- The Hungarian Hospice Palliative Association - as the national palliative care association of Hungary - coordinates more than 80 hospice organisations across the country. The association has been a collective member of the European Association of Palliative Care (EAPC) since 1999 and a member of the International Association of Hospice and Palliative Care (IAHPC) since 2011. The main collaboration with the EAPC is the Eastern European E-mail Palliative Care Newsletter, edited by the EAPC and the Hungarian Hospice Palliative Association (and supported by Open Society Foundation);
- Pioneers include: Hungarian Hospice Foundation (Budapest); Charity Hospital of the MAZSIHISZ (Budapest); research group of the Semmelweis University, Budapest; Katalin Muzsbek (Hungarian Hospice House, Budapest);
- World Hospice and Palliative Care Day is celebrated by the Hungarian Hospice-Palliative Association and almost 20 other organisations throughout Hungary (<http://www.hospice.hu/en/programs/world-hospice-and-palliative-care-day/484>).

Worldwide palliative care alliance level of development:

4A (Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

Development has been mostly quantitative: the hospice minimum standards require every hospice worker (of any profession) to complete a basic hospice course of a minimum 40 hours duration.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: 30 hours palliative care (and/or thanatology) accredited courses at every medical faculty (four in the country) (optional - for two to four credits depending on individual faculties);
- Nursing: 20 hours hospice/palliative care module;
- Social work: 26 hours "special hospice knowledge";
- Other professions: 90 hours for physiotherapy students (optional - for three credits).

Specific developments in post-graduate palliative care education initiatives:

- Medicine: Eight to 16 hours hospice/palliative care courses; 40-80 hours hospice/palliative care practice;
- Nursing: 40 hours hospice/palliative care basic course; 800 hours skilled hospice nurse course;
- Social work: 40 hours hospice/palliative care basic course;
- Other professions: 40 hours hospice/palliative care basic course;

Translation of palliative care documents or other materials:

- Kathleen M. Foley (2005): The Past and Future of Palliative Care. Improving End-of-life Care. Why Has It Been So Difficult? Hasting Center Report Special Report 35 (6): S42-S46 (http://www.kharon.hu/docu/2006-1-2_kathleen-palliativ.pdf);
- Centeno, C., Clark, D., Rocafort, J., Flores, L. A., Lynch, T., Prail, D., De Lima, L., Branch, S., Greenwood, A., and Giordano, A. 2007. Facts and indicators on palliative care development in 52 countries of the WHO European region: results of an EAPC Task Force. *Palliative Medicine*, 21: 463 (http://www.kharon.hu/docu/2006-3-4_carlos-tenyek.pdf);
- IMPaCCT: Standards for Paediatric Palliative Care in Europe. *European Journal of Palliative Care* 2007, 14 (3): 109-114.
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- http://www.ipos-society.org/education/core_curriculum/core_curriculum_hu.aspx;
- Radbruch, L. et al., White paper on standards and norms for hospice and palliative care in Europe - part 1. Recommendations from the European Association for Palliative Care. *European Journal of Palliative Care* 2009, 16 (6): 278-289 (http://www.kharon.hu/docu/2010-3_lukas-feher-1.pdf);
- Radbruch, L. et al., White paper on standards and norms for hospice and palliative care in Europe - part 2. Recommendations from the European Association for Palliative Care. *European Journal of Palliative Care* 2010, 17 (1): 22-34 (http://www.kharon.hu/docu/2010-3_lukas-feher-2.pdf).

Initiatives to develop healthcare professional leadership in palliative care:

- Leadership Development Program, San Diego Hospice, Institute for Palliative Medicine, San Diego, CA, USA, Open Society Institute (Dr Ágnes Csikós, 2009-2011);
- ELNEC program (2011) (six hospice/palliative care training sessions in Hungary);
- ERASMUS Program (on hospice/palliative care) - Bologna University (Italy) and Semmelweis University (Budapest).

Officially recognized medical certification:

- A specialty in hospice nursing exists in Hungary, which is one year in duration and consists of a total of 800 hours education and training (400 hours of lectures and 400 hours of clinical practice) (http://www.hospice.hu/en/standards/91_pp_94-100). The authority that certifies the accreditation process is the Health and Vocational Training Institution. The first healthcare professionals were accredited in 2002; to date, approximately 450 healthcare professionals have been accredited in this way;
- In process: a Sub-specialty is being prepared supported by the Hungarian College of Oncology; the estimated date of accreditation is 2012.

Capacity of palliative care workforce training in Universities and Medical Schools:

- Hungary has four medical schools - all of them have palliative medicine as an optional component (source: personal and official contacts);
- There are approximately five full professors, ten assistant professors, and ten "other professors" in palliative medicine.

Financial support for palliative care has been provided by the National Health Insurance Fund. Public awareness of palliative care has improved. Significant international recognition was received when the 10th EAPC Congress was held in Budapest in 2007

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

Most essential medications are available.

Developments/opportunities/barriers relating to the accessibility of essential medications:

It may be difficult to access medications at weekends. Pharmacies do not always stock opioids (apart from the major ones) and if they have to order them it can take some time.

Developments/opportunities/barriers relating to the affordability of essential medications:

The cost of slow-release opioids is covered (patients pay only a “box fee” of one Euro) but the cost of immediate-release opioids is not (patients often cannot afford to pay for them).

Initiatives to change regulations that may restrict physician or patient access to pain relief:

- Reduce strict regulations (e.g. accessibility to methadone).
- Change regulations to prescribe opioids in different indications (and for non-cancer patients).

Initiatives to promote attitudinal change in relation to ‘opiophobia’:

- Free training for doctors, nurses and volunteers (sponsored by the pharmaceutical companies).
- Required education on pain management at undergraduate level.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

Access to opioid medication is free for economically disadvantaged persons.

Initiatives that consider access to essential medication as a legal and human right:

As above.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- National Cancer Control Program (2006);
- The third version of the National Palliative Care Standards - Professional Guidelines of Palliative Care of Terminally Ill Cancer Patients (edited by the Ministry of Health in 2010);
- Recommendations from the National Health Council about palliative care development (2010).

The impact of these policy changes and ways in which they have been important:

These changes have been important because they have provided policy makers with more official knowledge about palliative care.

Development of a national palliative care consensus:

- Consensus conferences on minimum palliative care standards (2007-2008);
- Consensus conferences on paediatric hospices (2009-2010);
- Consensus conference on special licence examination for palliative care physicians (2010).

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

As above.

Development of an advocacy framework for integrating palliative care into the health care system:

- Organization of the 10th Congress of the European Association for Palliative Care in Budapest (52 media releases);
- Participation in the National Health Council between 2006 and 2010.

Strategies to improve political awareness and government recognition of palliative care:

- Continuous contact with health policy makers;
- Lobbying activities at different congresses (for example, oncological congresses);
- National palliative care meetings (annually);
- National palliative care congresses (bi-annually);
- Consensus conferences (as above).

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

- There has been much funding provided by donors;
- Open Society Foundation support;
- EAPC support;
- Four ELNEC programs have been funded.

Involvement with the European Union in relation to hospice and palliative care initiatives:

- EAPC collective membership (since 1999);
- Participation within the Board of Directors of the EAPC (2003-2010);
- Edition of the CEE&FSU Newsletter (2005-Present);
- Participation in different EU projects: Budapest Commitment survey (2007-2009); Moreno project of EU - Comprehensive Study on Palliative Care in the European Union (2008); ESMO-EAPC survey on opioid availability (2009); White paper on Standards and Norms (2007-2009); EAPC Basic Dataset survey (2010-2011); Needs assessment survey (NEED-IT) (2010-Present).

Development of initiatives framing palliative care as a ‘human right’:

As above.

General legislation relating to palliative care:

- Palliative care in the Health Care Act (1997);
- National Palliative Care Guidelines (2000, 2002, 2010);
- Minimum palliative care standards (2004);
- Financing Rules (NHIS, 2004, 2008);
- Palliative care in National Health Council (2006-Present);
- Palliative care in National Cancer Control Program (2006); (<http://www.hospice.hu/en/standards/>) (<http://www.hospice.hu/jogszabalyok/>)

Published national documents relating to palliative care standards and norms:

Online version: <http://www.hospice.hu/en/standards/g1> <http://www.hospice.hu/jogszabalyok/rendeletek/209> (First posted 2002; latest posting 2010).

National Plan or Strategy of Palliative Care:

Palliative care is included in the National Cancer Control Programme (<http://www.hospice.hu/en/standards/g5>).

National Cancer Control Strategy:

As above.

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy but it does not contain an explicit reference to palliative care provision.

National Primary Health Care Strategy:

There is no National Primary Health Care Strategy.

Designated policy maker for the delivery of palliative care services:

There is no designated policy maker for the delivery of palliative care services.

Department of Health specific responsibility for the delivery of palliative care services:

The Ministry of Health (Nursing Department) has specific responsibility for the delivery of palliative care services.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

Systems of auditing, evaluation and quality assurance are provided by the National Health Insurance Service.

Opioid legislation/Pain guidelines:

- Opioid legislation: http://www.elimed.hu/upload/pdf/eros_hatasu_fajdalomcsillapitok_rendelete_a_hatalyos_jogszabalyok_alapjan-1236.pdf
- Pain guidelines: Printed version: Hegedus K – Szy I (ed.): Palliative Care of Terminally Ill Cancer Patients. Professional Guidelines. Budapest, Hungarian Hospice-Palliative Association, 2002. (Published in English and in Hungarian);
- Az Egészségügyi Minisztérium szakmai irányelve a terminális állapotú daganatos felnőtt és gyermek betegek hospice és palliatív ellátásáról, 2010. Március 25-i Egészségügyi Közlönyben (LX évfolyam, 7.szám 1.458 - 1.547) (First edition 2000; latest edition 2010) <http://www.hospice.hu/jogszabalyok/rendeletek/209>.

Funding of palliative care services:

- No payment is required for palliative care consultation or hospitalisation;
- Some payment may be required for medication;
- Funds for development: ELNEC fund for nursing education (2011) (and many small amounts of funding and donor support).

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006**Change in public awareness or perception of hospice and palliative care:**

- World Hospice and Palliative Care Day – 25-30 events are held throughout the country each year;
- The Daffodil program – 15-20 events are held throughout the country each year.

Major public discussion, debate or controversy about hospice and palliative care:

The National Health Council hosted a major meeting about hospice and palliative care in 2010.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

- There were 52 media releases following the 10th Congress of the European Association for Palliative Care in Budapest (2007);
- "Twenty years of hospice in Hungary" - jubilee media releases (2011).

Hospice or palliative care 'success' stories:

- The rapid development of the hospice home care system (it now has almost country-wide coverage);
- EAPC Congress in Budapest (2007);
- New version of the National Standards (Professional Guidelines of Palliative Care of Terminally Ill Cancer Patients, edited by the Ministry of Health in 2010);
- Recommendations from the National Health Council about the development of palliative care (2010).

Initiatives seeking the legalisation of euthanasia or assisted dying:

- Conference on euthanasia (Faculty of Law, Budapest, 2010);
- Proposal of an individual to the Constitutional Court to change (clarify) legislation relating to the right to refuse life-saving or life-sustaining treatment (2010).

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT**The future of hospice and palliative care development:**

- There needs to be more professional and policy recognition of palliative care.
- Further development of inpatient hospice-palliative care services is needed.

Most significant issues facing hospice and palliative care in the next three years:

- Palliative care qualifications for physicians;
- The financing system of mobile hospital teams, outpatient clinics and paediatric hospices;
- Develop a nationwide palliative care curriculum in undergraduate medical education;
- Establish a student hospice volunteer program and provide education about palliative care within schools;
- The role of the Hungarian Hospice Palliative Association (as the national association of palliative care in Hungary) is to continuously lobby policy makers in order to resolve these issues.

Implications for palliative care relating to the current economic crisis:

- Difficulty in developing inpatient palliative care;
- Financial restrictions by the National Health Insurance Fund (no reimbursement for breakthrough pain medications);
- Difficulty in finding additional financial sources for palliative care development (e.g. donors);
- Overworked colleagues (burnout syndrome).

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Iceland¹

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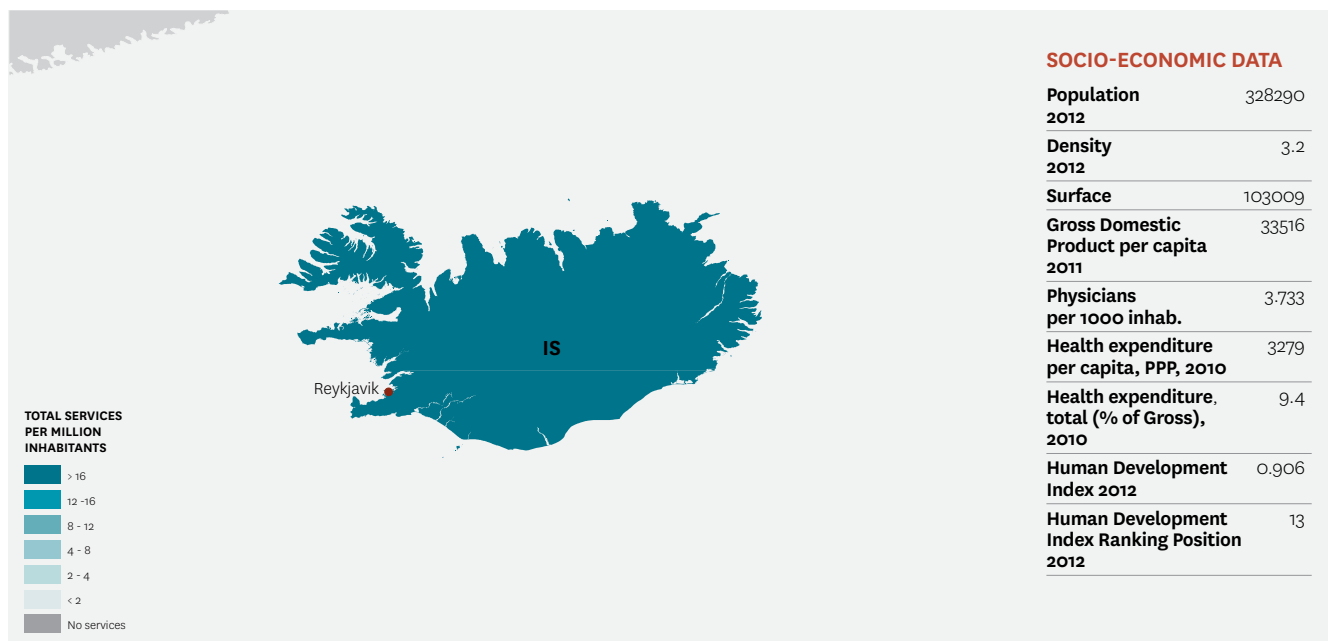
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|--|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 1 (n/a) |
| Home palliative care support team | 4 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 2 (integrated into one, March 2012) (17) |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 0 |
| Day hospice/day care centre | 1 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Landspítali - the National University Hospital;
- The Icelandic Health Insurance.

Additional comments:

- The palliative care consultation team operates at Landspítali - the National University Hospital (NUH) in Reykjavik. The team gives consultation; two nurses have positions within the team (1.6) and there is access to two physicians, a chaplain and a social worker;
- Two home palliative care support teams are located in Reykjavik, the capital of Iceland. They serve around 200,000 people who live in the greater Reykjavik area. One team is a part of Landspítali - the National University Hospital; the other team has a contract with the Icelandic Health Insurance. A third team is located in the northern part of the country in the second biggest town in Iceland, Akureyri; they also have a contract with the Icelandic Health Insurance. The fourth home care team provides palliative care in the southern part of the country, Keflavik, an area serving around 20,000 people;
- Both palliative care units in tertiary hospitals are located at Landspítali - the National University Hospital. One unit is a geriatric unit (nine beds); the other is a general palliative care unit (eight beds). In conjunction with the general palliative care unit, another unit with four beds was opened in 2007 (this unit is only open five days per week). This has been a great source of support for the home-based palliative care services, as it has decreased unplanned hospitalization, and helped patients to stay longer at home;
- In November 2011, the hospital administration board decided to restructure palliative care services and a plan is in process to combine the two palliative care units in 2012.
- One day care centre was opened in 2007 (in conjunction with the general palliative care unit) and can accommodate eight to twelve patients (it is open twice per week); one nurse, one nurse assistant and one physiotherapist are in attendance at the day care centre and there is access to a physician, a chaplain and a social worker.

Palliative care services for children:

There is no information available at this time.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|-----------|--|
| 1987 | The first palliative home care team is started in Reykjavik by the Icelandic Cancer Society. |
| 1988 | The first oncological inpatient ward is opened. |
| 1992 | Two palliative home care teams are started, both nurse operated, one in Reykjavik and the other at Akureyri. |
| 1997 | A palliative care consulting team is started at the University Hospital in Reykjavik, seeing around 300 patients a year. |
| 1999 | A palliative care unit is established at the University Hospital with eight beds. |
| 2001 | A geriatric palliative care unit is established, with nine beds for cancer patients aged 67 years or older, and served by two geriatricians (both working part-time). |
| 2001 | The Department of Health appoints a working group on priorities within health care and publishes its minutes stating that palliative care comes second only to acute care. |
| 2003-2004 | Assessment of patients in palliative care services using the minimum data set for palliative care instrument (MDS-PC) is conducted in Reykjavik. |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- January 2006 - The home palliative care support team of the Icelandic Cancer Society was moved to the general Palliative Care Unit (PCU) at the National University Hospital (NUH);
- September 2007 - Opening of a five-day unit (Monday to Friday) with four beds at the PCU and a Day Care Centre for eight to twelve patients (open twice per week);
- Spring 2008 - Translation and adoption of the Liverpool Care Pathway (LCP) which is integrated into both general and geriatric PCUs and the Department of Oncology;
- December 2009 - Online Clinical Guideline on Palliative Care at the NUH and Directorate of Health adopted with permission from the Institute for Clinical Symptom Improvements <http://innri.lsh.is/Pages/14863?itemid=45f7bc71-8f49-431c-b5e0-8fed11ab9b49>;
- October 2010 to December 2011 - Integration of LCP into all clinical wards at the NUH (except the Children's Hospital) together with most nursing homes in the Reykjavik metropolitan area. LCP has also been integrated in two hospitals outside the metropolitan area - in Akureyri and Keflavik respectively (and local nursing homes);
- In 2011, the PCU became the Centre of Excellence for LCP in Iceland (contact person Svandís Iris Hálfðánardóttir RN MSc svaniris@landspitali.is);
- September 2012 - The general PCU increased the number of palliative care beds to 17 (13 beds available seven days per week, three beds available five days per week and one acute bed);
- Increased discussion has taken place within the health care system on the importance of palliative care; there has been official recognition of the importance of existing palliative care settings in Iceland.

Overall progress in hospice and palliative care:

Hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: Integration of LCP has taken place in all clinical wards at the NUH since 2010 and in two hospitals outside Reykjavik. The number of patients admitted to the hospital-based consultation team of the NUH has increased annually; in 2008 and 2009, 320 patients were admitted (each year) but in 2010 and 2011, there were 500 patients admitted (each year);
- Nursing homes: Integration of LCP has taken place in the Reykjavik metropolitan area since 2010 and in two nursing homes outside Reykjavik;
- Residential homes for the elderly: No development;
- Other community settings: There has been increased co-operation between the community nursing services in the Reykjavik metropolitan area and the two specialized palliative home care teams (that act on a consultation basis).

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

Since 2009, an increased focus has been placed on patients with end-stage heart failure and COPD; however, 'non-cancer' patients still represent less than 5% of all patients admitted to palliative care settings.

Perceived barriers to the development of hospice and palliative care:

- There have been no official directives from the Department of Health on standards of palliative care or the structure of palliative care services in Iceland;
- No formal palliative care education programmes are available for medical or nursing students at Icelandic universities;
- There is a severe lack of doctors specialized in (or interested in) palliative care.

Perceived opportunities for the development of hospice and palliative care:

- Increased interest in palliative care among health care professionals and the general public;
- An increased number of patients are admitted to palliative care services in the Reykjavik metropolitan area;
- There has been a small amount of growth in palliative care research.

Other issues relevant to the development of hospice and palliative care:

- Participation of two Icelandic physicians in the educational program of the Nordic Specialist Course in Palliative Medicine (www.nscpm.org);
- Continued economic support from the Oddfellow Order in Iceland (to renovate the general PCU at the NUH).

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

The Life, Icelandic Association for Palliative Care (Lífið, samtök um líknarneðferð á Íslandi) was formed in 1997; the association has a website (<http://lsl.is/index.php>) and is representative of the whole country.

Directory or catalogue of palliative care services:

- A directory of palliative care services is in process;
- The first published Palliative Care Guidelines in Iceland (Dec. 2009) include a chapter on specialised palliative care services (the country has not many inhabitants so specialised palliative care services are few).

Congresses, scientific meetings or scientific journals in palliative care:

- The Icelandic Association of Palliative Care annually organises a one-day seminar for healthcare professionals that focuses on different areas of palliative care (prior to 2008, the seminars were organised two or three times each year). The seminar is attended by approximately 50-60 people;

- The Nursing Faculty of the University of Akureyri (in the Northern part of Iceland) biannually hosts a one-day seminar on different aspects of palliative care. The seminar is attended by approximately 60-80 people.

Palliative care research capacity:

There are a few individuals engaged in palliative care research in Iceland: Gudlaug Helga Ásgeirsdóttir (chaplain at the General Palliative Care Unit - PhD study on spiritual issues within palliative care); Sigríður Gunnarsdóttir (RN - pain resource nurse - PhD study on implementation and evaluation of the PRN program also includes palliative care services); Sigríður Helgadóttir (MD - Master's thesis on prognostic factors in advanced cancer); Valgerður Sigurðardóttir (MD, PhD - participates in different research projects such as European Pharmacogenetic Opioid Study (EPOS) (with Sigríður Gunnarsdóttir) and is co supervisor of PhD projects and Master's theses).

Palliative care collaboration:

- In Iceland, there are approximately 300,000 inhabitants and the majority of people (approximately 200,000) live in the greater Reykjavik area; consequently, there are not many institutions providing specialized palliative care within the official health care system. Distances between service providers are relatively short and communication is often on a personal level between healthcare professionals;
- The Nordic Specialist Course in Palliative Medicine is a joint venture between the Associations for Palliative Medicine in the five Nordic countries and the Marie Curie Palliative Care Institute in Liverpool, UK. Valgerður Sigurðardóttir has participated in development of the Nordic Specialist Course in Palliative Medicine since it first began;
- The general palliative care unit also has collaboration with the Marie Curie Palliative Care Institute in Liverpool regarding implementation of the Liverpool Care Pathway. The project leader is Svandís Íris Hálfánardóttir and the physician responsible for implementation is Valgerður Sigurðardóttir;
- The development of palliative care in Iceland was initially based on the work of pioneers and enthusiastic individuals, but in the last decade palliative care has become established within the official health care system and is now considered as a fundamental part of the health care service. Important developments since 2006 include: the palliative home care team of the Icelandic Cancer Society became a part of Landspítali - the National University Hospital (2006); a unit open five-days per week (four beds), a day care center and an outpatient unit were established in conjunction with the general palliative care unit (2007); guidelines on palliative care were published online at Landspítali - the National University Hospital (2009);
- Since 2005, the Icelandic Association of Palliative Care has promoted World Hospice and Palliative Care Day. There have been miscellaneous initiatives such as: an "open house" for the public - the introduction of palliative care services in Iceland; a video on palliation (broadcast on RUV1, Icelandic State TV); seminars on palliation; interviews on radio and TV; and the translation of a brochure for relatives of dying patients regarding symptoms and changes that occur during the last days of life (translated from Swedish, author Ulla Söderström).

Worldwide palliative care alliance level of development:

4B (Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:
There is no information available at this time.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Still no development. There is only one lecture on palliative care in the fourth year and one lecture on pain management in the sixth year;
- Nursing: There are some lectures about palliative care nursing within the course on oncological nursing (in the third year);
- Social work: No development;
- Other professions: No development.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: No development;
- Nursing: A Master's course in palliative care at the University of Iceland, Faculty of Nursing is available biannually; a Master's course in palliative care and oncological nursing at the University of Akureyri, Faculty of Health Care is available biannually;
- Social work: No development;
- Other professions: No development.

Translation of palliative care documents or other materials:

- Clinical guidelines on palliative care from the Institute on Clinical Symptom Improvement in 2009 (www.icsi.org);
- The Liverpool Care Pathway in 2008.

Initiatives to develop healthcare professional leadership in palliative care:
There is no information available at this time.

Officially recognized medical certification:

Iceland participates in the Nordic physician education program Nordic Specialist Course in Palliative Medicine (www.nscpm.org). The course, a joint venture between the Associations for Palliative Medicine in the five Nordic countries, consists of theoretical specialist training within six modules over the course of two years. The course is developed for physicians who have been trained as specialists in relevant clinical specialities but require expertise in palliative medicine at the specialist level. The aim of the course is to equip doctors with the necessary skills required as a consultant working full-time in a specialist palliative care setting with responsibility for a substantial numbers of patients with late-stage disease.

Capacity of palliative care workforce training in Universities and Medical Schools:

There is one medical school at the University of Iceland. There is no formal education in palliative medicine in the country. Within the nursing faculty at the University of Iceland a multi-professional palliative care course has been available since 2010 at Master's degree level. The nursing faculty at the University of Akureyri (in the northern part of the country) also offers a course on oncology and palliative care for nurses at Master's degree level.

The home palliative care team of the Icelandic Cancer Society has been moved to the Palliative Care Unit (PCU) at the National University Hospital (NUH). A five-day unit and a day care centre have been opened at the PCU

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

Oxycodone and oxynorm have been added to the list of available opioids (i.e. morphine, hydromorphone, fentanyl, methadone and buprenorphine).

Developments/opportunities/barriers relating to the accessibility of essential medications:

Any physician with unrestricted legislation can prescribe a 100-day dosage of opioids: online opioid prescription is now available.

Developments/opportunities/barriers relating to the affordability of essential medications:

All patients receiving palliative care services are entitled to free medication.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

Initiatives to promote attitudinal change in relation to 'opiophobia' include the introduction of clinical guidelines on palliative care and the LCP.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

Not needed.

Initiatives that consider access to essential medication as a legal and human right:

Not needed.

Development of an advocacy framework for integrating palliative care into the health care system:

There is no information available at this time.

Strategies to improve political awareness and government recognition of palliative care:

There has been much participation in a variety of medical and nursing educational meetings (both clinical and research), with interviews in newspapers, radio, etc. A Master's thesis (nursing) on standards and strategies of palliative care was sent to the Department of Health in 2009.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

Since 1999, the Oddfellow Order in Iceland has provided continued financial support for a number of initiatives: renovation of the PCU at the NUH; opening of the new unit and daycare centre in 2007; enlargement of the PCU unit in 2012.

Involvement with the European Union in relation to hospice and palliative care initiatives:

There is no information available at this time.

Development of initiatives framing palliative care as a 'human right':

The concept of palliative care as a 'human right' is stated in both the new clinical guidelines on palliative care and in the introduction of LCP.

General legislation relating to palliative care:

- There are no specific laws regarding palliative care services but the Patients' Rights Act No 74/1997 includes laws regarding a patient's right to refuse treatment and right to die with dignity. Art. 24: "A terminal patient has the right to die with dignity. If a terminal patient unambiguously indicates that he/she declines further life-prolonging treatment, or resuscitation efforts, his/her physician shall respect his/her decision. If a terminal patient is mentally or physically too ill to take part in a decision on treatment, the physician shall endeavour to consult the patient's relatives, and his/her colleagues, before he/she decides on the continuation or cessation of treatment". Ref: Patients' Rights Act No 74/1997 (with amendments according to Acts 77/2000, 40/2007, 112/2008 and 55/2009);
- At the Directorate of Health, a Living Will has been available since 2005.

Published national documents relating to palliative care standards and norms:

There are no national documents relating to standards and norms of palliative care services in Iceland. The Guidelines of Palliative Care include: a definition of general and specialised palliative care; which groups of patients could benefit from palliative care; and a list of services providing specialized palliative care in Iceland.

National Plan or Strategy of Palliative Care:

In 2011, the Ministry of Welfare started work on preparation of a National Cancer Plan which will include palliative care; no estimated date for completion is available.

National Cancer Control Strategy:

Cancer treatment in Iceland is centralised at Landspítali - the National University Hospital.

National HIV/AIDS Strategy:

There is no information available at this time.

National Primary Health Care Strategy:

The Icelandic National Health Plan has been published annually from 2001 to 2010. It contains little reference to palliative care except to state that is ranked as the second priority area (behind healthcare service to people who are seriously injured and patients with life-threatening disease); the plan also indicates in the chapter regarding prioritizing the health care system that treatment and care of patients close to death should take into account the patient's and/or relatives wishes and should be "as considerate as possible". A new strategy will be issued in 2012.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- In Spring 2007, the medical and nursing board of the NUH asked the hospital-based consultation team to develop new clinical guidelines on palliative care;
- In October 2011, the Executive Board of the NUH ordered the LCP project group at the PCU to integrate LCP in all clinical wards of the hospital.

The impact of these policy changes and ways in which they have been important:

- The introduction and integration of both the clinical guidelines on palliative care and the LCP has provided several educational opportunities in all clinical wards at the NUH and within nursing homes;
- There has been increased use and documentation of a DNR-order in patients' notes together with documentation relating to communication on treatment decisions.

Development of a national palliative care consensus:

Publication of new online clinical guidelines on palliative care at the National University Hospital and on the website of the Directorate of Health together with the introduction of LCP.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

There is no information available at this time.

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

According to Patients' Rights and the Health Care Plan the Ministry of Welfare is responsible for delivering palliative care services to patients.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- Any doctor who is fully licensed can prescribe opioids. Patients have the right to a 100-day prescription. Opioids are available from all pharmacies but when they are delivered the patient has to sign the prescription and show official identification before they can receive them.
- In December 2009, the first Palliative Care Guidelines were published online. In these guidelines there is a chapter on pain management in palliative care (in Icelandic). In 2010, clinical guidelines on cancer pain management were published.

Funding of palliative care services:

- There is no payment required for palliative care consultation or hospitalisation.
- Patients do not have to pay for medication used in palliative care but they may have to partially pay for some other medications.

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006**Change in public awareness or perception of hospice and palliative care:**

There has been an increase in both knowledge and awareness about hospice and palliative care.

Major public discussion, debate or controversy about hospice and palliative care:

There is no information available at this time.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

- There have been many interviews in newspapers and on radio and TV (for example, news on the potential closing of the geriatric PCU due to economic restrictions);
- In 2012, a brochure on palliative care will be provided for the general public in collaboration with the Directorate of Health;
- A mini-seminar on palliative care is provided for the general public on World Hospice and Palliative Care Day.

Hospice or palliative care 'success' stories:

There is no information available at this time.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is no information available at this time.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT**The future of hospice and palliative care development:**

Palliative care services are now permanently integrated into the official health care system although statements on priorities are still lacking from the Department of Health. Work on ensuring palliative care beds are available in nursing homes in the Reykjavik metropolitan area has started. Priorities in the next ten years will be developing palliative home care services - both as specialized ones and as consultation teams working in conjunction with the district home-care teams - and increased work through hospital palliative care consultation teams. Furthermore, palliative care for patients with non-malignant diseases will continue to develop. Hopefully, palliative care education in the under-graduate system of medicine and nursing will be provided.

Most significant issues facing hospice and palliative care in the next three years:

- Incorporate palliative care education into the under-graduate system of medicine and nursing. This is the joint responsibility of the leaders of the PCU and the executive directors of medical and nursing education at the NUH in collaboration with the Faculties of Medicine and Nursing at the University of Iceland;
- Lack of palliative care physicians; there is a need to continue the participation of the Icelandic Association of Palliative Care in the Nordic Specialist Course in Palliative Medicine: there is also a need to continue to recruit medical students at the PCU (as is currently being done with nursing students and nursing assistants). This is the joint responsibility of the medical director of the PCU and the executive director of medical education at the NUH;
- Integrate PCU in the post-graduate educational programme of internal medicine at the NUH. This is the joint responsibility of the medical director of the PCU and the executive director of medical education at the NUH;
- Continue to provide palliative care to the non-cancer population. This is the joint responsibility of the Icelandic Association of Palliative Care, the PCU and the hospital-based consultation team at the NUH.

Implications for palliative care relating to the current economic crisis:

- Fewer inpatient wards with specialized palliative care beds;
- Increased workload for palliative home care staff, the hospital-based consultation team and palliative care services in other clinical units of hospitals;
- A lack of educated palliative care physicians is already a great problem and will be one of the main challenges to face in the future.

References

Haugen DF, Vejlggaard T. 2008. "The Nordic Specialist Course in Palliative Medicine: evaluation and experiences from the first course 2003-2005". *Palliat Med*; 22(3):256-63.

Emilsdóttir AL, Gústafsdóttir M. August 2011. "End of life in an Icelandic nursing home: an ethnographic study". *International Journal of Palliative Nursing*; 17 (8): 405-11.

The number of patients admitted to the hospital-based consultation team of the NUH has increased annually, with an increased focus on patients with end-stage heart failure and COPD. There has been increased co-operation between community nursing and home care teams

Ireland¹

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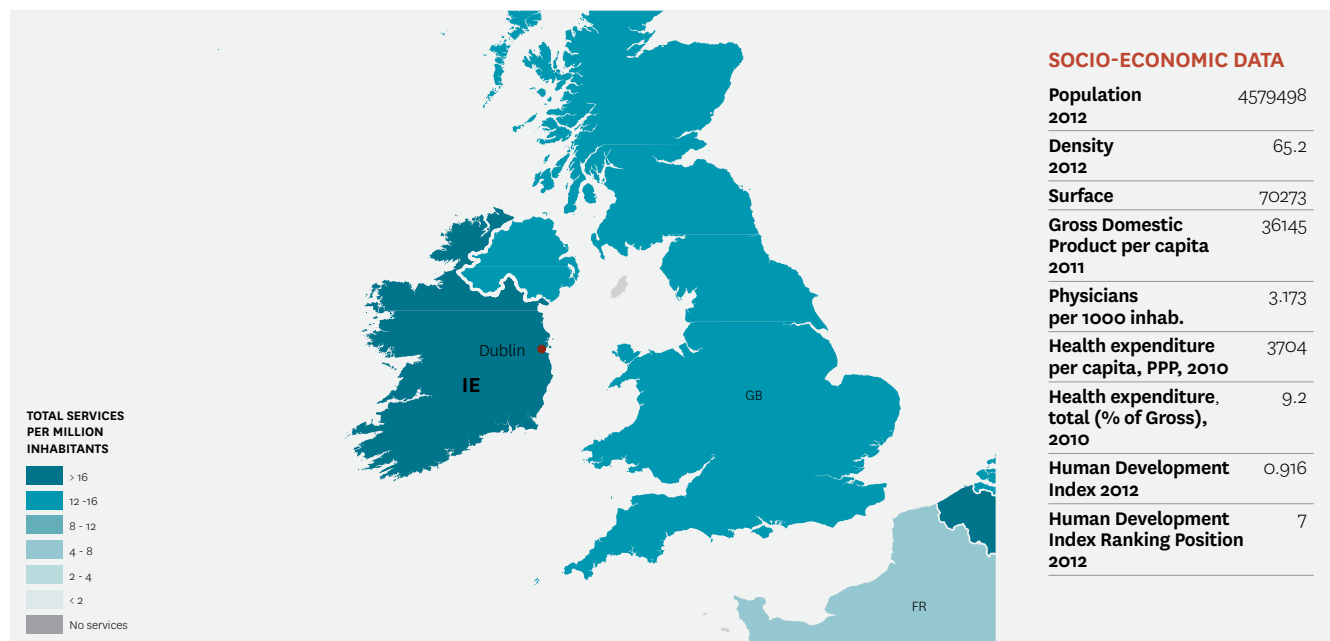
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|--------------------------------|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 39 |
| Home palliative care support team | 35 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 0 |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 9 + 1 Children's Hospice (156) |
| Day hospice/day care centre | 7 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Directory of Specialist Palliative Care Services in Ireland 2012, Irish Association for Palliative Care (IAPC).
- Health Service Executive (HSE).

Additional comments:

- The Report of the National Advisory Committee on Palliative Care (Department of Health, 2001) represents national policy for palliative care in Ireland. Guidance on the structure and staffing of palliative care services is provided in the Report. In Ireland, palliative care services are structured in three levels of ascending specialisation. These levels refer to the expertise of the staff providing the service:

- Level one – Palliative Care Approach: Palliative care principles should be appropriately applied by all health care professionals.
- Level two – General Palliative Care: At an intermediate level, a proportion of patients and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care.
- Level three – Specialist Palliative Care: Specialist palliative care services are those services whose core activity is limited to the provision of palliative care.
- The specialist palliative care unit is the core essential element of the Specialist Palliative Care service, and acts as a co-ordinating centre for the delivery of Specialist Palliative Care services in all care settings.
- Consult Advisory Services in the acute hospitals are delivered by Specialist Palliative Care teams comprised of palliative medicine consultants with registrars, clinical nurse specialists in palliative care, and allied health professionals (such as social workers and secretarial support);
- The home palliative care support team services include services provided by hospices and those provided by 32 Health Service Executive (HSE) Local Health Offices (LHO) (i.e. State-run local community services providing a range of health related services - GPs, public health nurses, etc.). Each Local Health Office is served by a Specialist Palliative Care Home Care team.

Palliative care services for children:

- Ireland's first Consultant Paediatrician with a Special Interest in Paediatric Palliative Medicine was appointed in 2011, based at Our Lady's Children's Hospital Crumlin, Dublin.
- National policy provides for eight dedicated Children's Palliative Care Outreach Nurses to be in place by 2013
- There is one children's hospice in Ireland – LauraLynn Ireland's Children's Hospice, Dublin – established 2011.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|------|---|
| 1993 | Irish Association for Palliative Care established as an all island of Ireland professional membership association. |
| 1994 | The <i>Health Strategy, Shaping a Healthier Future</i> (Department of Health, 1994), recognised the role of palliative care services in improving quality of life for patients and their families and Government committed to developing services in a structured manner. |
| 1995 | Ireland became the second country in Europe to recognize palliative medicine as a distinct medical specialty. |
| 1996 | <i>Cancer Services in Ireland: a National Strategy</i> (Department of Health, 1996) underlined the requirement for expansion of palliative care services. |
| 1996 | <i>Position Paper on the Development of Hospice and Specialist Palliative Care Services in Ireland</i> (Irish Association for Palliative Care (IAPC), 1996) supported the development of palliative care in Ireland. |
| 1999 | The National Advisory Committee on Palliative Care (NACPC) established by the Minister for Health. |
| 2001 | The <i>Report of the National Advisory Committee on Palliative Care</i> (Department of Health, 2001) was published. The Report represents national policy for the development of palliative care services in Ireland. |
| 2003 | Publication of the Council of Europe Report - <i>Recommendation REC 24 (2003) of the Committee of Ministers to member states on the organisation of Palliative Care</i> - defined a new standard in palliative care provision across the 45 member states of the Council of Europe. |
| 2005 | National Council for Specialist Palliative Care established by the Minister for Health. |
| 2005 | <i>A Baseline Study on the Provision of Hospice/Palliative Care Services in Ireland</i> (Irish Hospice Foundation, 2006) - conducted in 2005 and published in 2006, this was the first systematic nationwide review of the state of palliative care services in Ireland. |

EAPC Palliative Care Euro-Barometer 2005

There has been increased recognition of the importance of palliative care for people with non-malignant disease. An academic focus within palliative care practice has been further developed by increased resource allocation, improved partnerships with universities, policy development and international discourse

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- 2010: the Palliative Care Programme was established within the Health Service Executive (HSE) Clinical Strategy and Programmes Directorate. This has represented a significant enabler for developing clinical strategy for palliative care in Ireland. The objectives of the Palliative Care Programme are to strengthen clinical leadership, improve clinical performance, and ensure care is delivered in a manner that maximises quality and efficiency.
- 2012: the Health Service Executive (HSE) Integrated Services Directorate (ISD) and the HSE Palliative Care Programme established a partnership, taking a joint collaborative approach to the strategy, policy, governance, and operations dimensions of Palliative Care delivery within the HSE.
- 2012: The Health Service Executive (HSE) Palliative Care Competence Framework: the development of Ireland's first Palliative Care Competence Framework for health and social care professionals working in various healthcare settings is a significant contribution to the development of palliative care. The framework details the core competences in palliative care as well as detailing individual competences for each health and social care discipline. In due course the Framework will inform academic curricula and professional development programmes.
- A key policy focus since 2010 has been on palliative care for children. *Palliative Care for Children with Life-Limiting Conditions in Ireland - A National Policy* (Department of Health, 2010) was adopted as national policy in 2010.
- 2010: the Health Service Executive (HSE) National Development Committee for Children's Palliative Care was established with oversight responsibility for implementation of the national policy for children's palliative care (2010). This includes the appointment of Ireland's first Consultant Paediatrician with a Special Interest in Paediatric Palliative Medicine (2011), and eight Children's Palliative Care Outreach Nurses.
- Palliative Care and non-malignant diseases: there has been increased recognition of the importance of palliative care for people with non-malignant disease (*Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks* (HSE and Irish Hospice Foundation, 2008)). This change has been assisted by public debate, policy development, and increased resource allocation and re-structuring of healthcare services to meet the needs of those with chronic disease.
- An academic focus within palliative care practice has developed further. Maturation of the specialty, along with increased resource allocation, improved partnerships with universities; policy development and international discourse have all contributed to this change.
- 2010: the All Ireland Institute of Hospice and Palliative Care (AIHPC) was established in October 2010. It is an all island of Ireland (Republic of Ireland and Northern Ireland) organisation, comprised of a twelve-member consortium including five hospices and five universities, working collaboratively to improve the experience of supportive, palliative and end-of-life care on the island of Ireland, by enhancing the capacity to develop knowledge, promote learning, influence policy and shape practice.

Overall progress in hospice and palliative care:

- Since the Report of the National Advisory Committee on Palliative Care (Department of Health, 2001), successive Ministers for Health have supported the recommendations of the Report. The commitment of the Department of Health and the Health Service Executive (HSE), along with investment and the significant contribution of the voluntary hospice movement, has resulted in greatly improved availability and provision of palliative care in Ireland.
- The Economist Intelligence Unit Quality of Death Index 2010 ranked Ireland as the 4th best place to die in the world (after the United Kingdom, Australia, and New Zealand).

Development of hospice and palliative care in different health and social care settings:

- Hospitals: Specialist Palliative Care is provided by Specialist Palliative Care teams in all acute hospitals in Ireland. However, the staffing levels of teams are variable. Palliative care support beds are provided in a number of community hospitals across the country. The National Minimum Dataset for Palliative Care has been developed to include a dataset for specialist palliative care activity in the acute hospital setting: data collection will begin in 2013.

- Nursing homes: Community Specialist Palliative Care teams provide services to nursing homes in all areas of the country. However, there has not been a systematic approach to the development of generalist palliative care skills in nursing homes.
- Residential homes for the elderly: As for nursing homes above
- Other community settings: There are community Specialist Palliative Care teams based in every Health Service Executive (HSE) Local Health Office (LHO) across the country. However, the staffing levels of teams remain variable.
- Children's Palliative Care: Development of a children's dataset is scheduled for full national roll-out in 2013.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

There has been an annual increase in patients with non-malignant diseases accessing specialist palliative care. National figures for homecare show an increase for these patients from 17% in 2010 to 24% in 2012 (HSE National Minimum Dataset for Palliative Care).

Perceived barriers to the development of hospice and palliative care:

- Resource constraints due to the national economic situation (e.g. recruitment pause, reductions in budget allocation)
- Lack of a systematic use of outcome measures to demonstrate the value of palliative care to the healthcare service.

Perceived opportunities for the development of hospice and palliative care:

- The Government's commitment to radical reform of the health service offers an opportunity for the strategic positioning of palliative care to deliver a patient-centred, high-quality and effective service that is excellent value for money.
- Opportunities exist in the Government's plans to provide free GP care for all, along with Universal Health Insurance by 2016. The Government has also given a strong undertaking to restructure the health service towards a more centralised approach.
- The restructuring of the health service presents opportunities as an integrated model of palliative care provision is increasingly recognised as being central to effective chronic disease management programmes.
- Introduction of prospective funding in 2014 by the Department of Health will provide an opportunity for "money to follow the patient". However, this is only an opportunity if diagnostic-related categories can be developed which accurately capture activity and cost.
- There is evidence of collaboration between specialist and generalist palliative care providers working together to develop palliative care services. This indicates significant opportunities for wider provision of palliative care.

Other issues relevant to the development of hospice and palliative care:

- The development of professional capacity and competence for the delivery of palliative care is a strategic imperative in order to meet current and emerging demands posed by societal and demographic trends. Ireland has an ageing population with concurrent increase in the prevalence of chronic disease. There is growing public awareness and discourse about death and dying, and about the quality and safety of healthcare provision. These are indicators that the need for a well-resourced national palliative care service is growing.
- The emerging need for the integration of palliative care into general disease management, and the development of a general palliative care approach for non-palliative care specialists, also place more demand on palliative care services.
- Economic policy for the health service is focussed on achieving efficiencies and bringing down costs: palliative care delivery can be demonstrated to provide efficiencies, cost savings and value for money while maintaining quality and patient safety.

In 2010, the Palliative Care Programme was established within the Health Service Executive (HSE) Clinical Strategy and Programmes Directorate. The HSE Integrated Services Directorate (ISD) and the HSE Palliative Care Programme established a collaborative partnership in 2012

Victality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

The Irish Association for Palliative Care (IAPC) was established in 1993. IAPC is the sole representative multidisciplinary professional membership body for palliative care professionals in Ireland. It is a structured sharing and learning network, its objectives being to develop capacity in palliative care through education and research and to shape national policy through being the expert voice for palliative care. The IAPC Knowledge Centre and further information can be accessed at web address www.palliativecare.ie.

Directory or catalogue of palliative care services:

- Directory of Specialist Palliative Care Services in Ireland 2012, (Irish Association for Palliative Care (IAPC), 2012).
- IAPC Directory of Specialist Palliative Care Services 2012 Online at: www.palliativecare.ie.

Congresses, scientific meetings or scientific journals in palliative care:

- Irish Association for Palliative Care (IAPC) Annual Conference (national level).
- Irish Association for Palliative Care (IAPC) Annual Education and Research Seminar (national level).
- Annual Kaleidoscope International Palliative Care Conference – St Francis Hospice, Dublin (national level).
- Moving Points Annual Palliative Care Conference – Our Lady's Hospice and Care Services, Dublin (national level).
- Cuisle Beatha International Palliative Medicine Conference – Galway University Hospital (national level) (biennial).

Each congress attracts in excess of 100 delegates.

Palliative care research capacity:

- The Irish Hospice Foundation (founded in 1986 to promote End-of-Life care and to engage in patient advocacy) undertakes research and publishes regularly in collaboration with the Health Service Executive (HSE) and other palliative care stakeholders.
- Irish university Schools of Nursing and Midwifery have an academic research portfolio.
- Irish hospices have dedicated Education and Research Centres which promote research in palliative care.
- The Irish Association for Palliative Care (IAPC) Education & Research Forum is a working group of the Association dedicated to promoting and accelerating evidence-based research in palliative care. IAPC publishes original research.
- Data and a catalogue on palliative care research activity in Ireland are available online at the IAPC Knowledge Centre www.palliativecare.ie or contact info@iapc.ie.
- The All Ireland Institute of Hospice and Palliative Care (AIHPC), with co-funding from the Health Research Board (HRB), has established the Structured Research Network - a multidisciplinary group of researchers on the island of Ireland that will work collaboratively to develop and produce innovative, high-quality research in palliative and end-of-life care.
- A systematic review of palliative care research in Ireland is underway at the All Ireland Institute of Hospice and Palliative Care (AIHPC). A report on preliminary findings can be accessed at www.palliativecare.ie/knowledge-centre.php.

Palliative care collaboration:

- There is a long tradition in Ireland of collaboration between the voluntary sector and the Health Service for the provision and delivery of hospice and palliative care (For example, Our Lady's Hospice, Harold's Cross, Dublin was established in 1875 and Marymount Hospice Cork was founded in 1879). The country has a strong voluntary hospice movement which seeks to work in partnership with the Health Service Executive (HSE) to strengthen and widen access to hospice and palliative care.
- Since 1987 the Irish Cancer Society has collaborated with Ireland's hospices and the health service to provide the free-of-charge Night Nursing Service for patients with cancer who require end-of-life care in their own homes. In 2012, 1,865 families availed of the Night Nursing Service.
- The Irish Hospice Foundation was founded in 1986 to promote End-of-Life care and to engage in patient advocacy. The Health Service Executive (HSE) and Irish Hospice Foundation partner on a number of programmes (such as the Hospice Friendly Hospitals (HfH) programme), education initiatives, and palliative care research and studies. Hospices also undertake research collaborations with the Irish Hospice Foundation.
- The Health Service Executive (HSE) and the Irish Hospice Foundation are partners in the development and provision of Children's palliative care services in Ireland, and are partners in the implementation of national policy for Children's Palliative Care through the HSE National Development Committee for Children's Palliative Care.
- The All Ireland Institute of Hospice and Palliative Care (AIHPC), established in 2010, is an all island of Ireland collaboration of hospices and universities and supported by statutory and voluntary bodies to promote palliative care through education, research and policy and practice development.
- The Irish Association for Palliative Care (IAPC) was established in 1993 as a body to promote palliative care collaboration on an all island of Ireland basis.
- There has been active collaboration on research projects between the IAPC Education and Research Forum and the EAPC Junior Research Network since 2012.
- The development of the Health Service Executive (HSE) Palliative Care Competence Framework (2012) represented a seminal collaboration of stakeholders – the HSE Palliative Care Programme, All Ireland Institute of Hospice and Palliative Care, Irish Association for Palliative Care, Irish Hospice Foundation, and HSE Office of the Nursing & Midwifery Services Director – which developed Ireland's first Palliative Care Competence Framework. Individual, discipline-specific competencies for each health and social care discipline providing palliative care from generalist through to specialist are detailed in the Framework.
- Palliative Care International Outreach collaborations/relationships include: Our Lady's Hospice Dublin and the Irish Hospice Foundation with Hospice Africa Uganda; Irish Association for Palliative Care (IAPC) with Chernobyl Children International (CCI) - Children and Babies Palliative Care development initiative in Belarus.

Worldwide palliative care alliance level of development:

4B (Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision).

The All Ireland Institute of Hospice and Palliative Care and the HSE National Development Committee for Children's Palliative Care were established in 2010 and the HSE Palliative Care Competence Framework was developed in 2012

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- There are improved opportunities for health and social care professionals to gain specialist palliative care education: academic departments in palliative care and in palliative medicine have been established (although there is significant geographical inequity in distribution); an increased number of interdisciplinary palliative care courses are provided at certificate, diploma and masters levels; there is evidence of increased collaborative activity between programme providers; the courses range from a specific focus on palliative care to Masters degree in End of Life Healthcare Ethics. However, there has been a relative lack of attention focused on training or education initiatives for allied health professionals.
- There are improved opportunities for generalists to gain palliative care education: the education departments of specialist palliative care units (hospices) commonly provide courses for generalists. The majority of these courses are accredited for Continuing Professional Development (CPD), but only a minority have university accreditation.
- There are improved opportunities for healthcare assistants to gain palliative care education. Level five education (National Framework of Qualifications) is provided and a palliative care module for healthcare assistants has been developed.
- Established in 2010, the All Ireland Institute of Hospice and Palliative Care (AIHPC) (www.aiihpc.org) has begun a programme of work in the area of education which brings the providers and consumers of education, and service users together to ensure that the required learning opportunities are available, accessible and of the highest quality. AIHPC has developed an Education Network involving the stakeholders of palliative care education and including the universities, hospice education teams, accreditation bodies, and relevant representation from users, carers and communities. This Network will help to prioritise key initiatives, and will implement appropriate sub-committees to drive specific initiatives. The Director(s) for Education and Training will play a key leadership role in the Education Network.
- The AIHPC Education Network (www.aiihpc.org) will assist in streamlining of education programmes for quality, efficiency and critical mass of education expertise across the island of Ireland; drive the availability of relevant education through commissioning of new palliative care education programmes where specific needs have been identified; develop greater accessibility of existing education programmes and collaborations for programme delivery working with key partners (e.g. the Irish Hospice Foundation (IHF), the Irish Association for Palliative Care (IAPC), and Northern Ireland Cancer Network (NICaNet)).
- HSE Palliative Care Competence Framework (2012): Ireland's first Palliative Care Competence Framework for health and social care professionals working in various healthcare settings was developed in 2012. The framework details the core competences in palliative care as well as detailing individual competences for each health and social care discipline. A stated purpose of the Framework is to inform academic curricula and professional development programmes.

Specific developments in under-graduate palliative care education initiatives:

Although there has been increased exposure to palliative care philosophy, principles and practice in undergraduate curricula since 2006, the increase and impact has not been standardised across the universities.

- Medicine: in 2012 Ireland's first Professor of Palliative Medicine was appointed jointly by TCD, UCD, and Our Lady's Hospice and Care Services. It is expected that this appointment will have a national role in further developing the undergraduate palliative care curriculum to ensure a consistent standard of education in this area.
- Nursing: in 2008 the Professor of Clinical Nursing Palliative Care was appointed jointly by UCD and Our Lady's Hospice and Care Services Dublin.
- Social work: no significant national development in this area.
- Other professions: no significant national development in this area.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: academic departments in palliative care and in palliative medicine have been established (although there is significant geographical inequity in distribution); an increased number of interdisciplinary palliative care courses are provided at certificate, diploma and Masters degree levels; there is evidence of increased collaborative activity between programme providers; the courses range from a specific focus on palliative care to a Master's degree in End of Life Healthcare Ethics; the number of training posts available for higher medical training in palliative medicine has increased; higher medical training curricula of disciplines such as geriatrics, general practice, respiratory medicine, etc., have been reviewed to recognise the importance of palliative care philosophy, principles and practice.
- Nursing: within six academic schools of nursing based in universities, post-graduate education in relation to specialist palliative care is offered at either graduate diploma or Masters Degree level.
- For generalists, the Irish Hospice Foundation's Hospice Friendly Hospitals (HfH) programme has developed a national practice development project for healthcare assistants and nursing staff in acute hospital and residential care settings on end of life care.
- The curricula of a number of nursing postgraduate courses have been reviewed to incorporate palliative care modules or content (e.g., MSc in Dementia includes a module 'Palliative Care: Supporting Persons with Dementia');
- A national programme for a short course of palliative care education for staff working in nursing homes has been developed and implemented.
- A series of short programmes/university modules at postgraduate level have been developed for nurses working in the field of palliative care for children. For example, the Health Service Executive (HSE), the Irish Hospice Foundation and the Centre of Children's Nurse Education together have developed and provide professional continuing education in the area of caring for children with life-limiting conditions.
- Social work: The HSE Palliative Care Competence Framework (2012) details competencies for social work generalist and specialist practitioners and will be used to inform curricula.
- All professions: Postgraduate Diploma /MSc in Bereavement Studies (Irish Hospice Foundation and the Royal College of Surgeons in Ireland (RCSI)). The HSE Palliative Care Competence Framework (2012) for generalist and specialist practitioners across the health professional disciplines will inform curricula in due course.

Translation of palliative care documents or other materials:

None

Initiatives to develop healthcare professional leadership in palliative care:

- All health education providers, including the Royal College of Physicians of Ireland (RCPI) and the Royal College of Surgeons in Ireland (RCSI), as well as the professional representative bodies, respond to the need for development of leadership capacity across the health service. Introduced in 2011, the Diploma in Leadership & Quality in Healthcare Management (RCPI) is a new initiative to develop leaders in the current health service with a particular focus on driving quality and patient safety. A number of palliative care health professionals have undertaken this programme.
- The All Ireland Institute of Hospice & Palliative Care (www.aiihpc.org) supports the development of capacity and leadership across the palliative care sector through individual learning and knowledge transfer between institutions, individuals and groups, on a national, cross-border, and international basis. The Institute has established a leadership programme with a focus on leadership process, and training and sustaining a pool of mentors (rather than managing specific mentoring relationships) based on international best practice in educational mentoring.

Officially recognized medical certification:

- Ireland has had specialist accreditation for palliative care physicians since 1995. Accreditation is provided by the Royal College of Physicians of Ireland (RCPI). The specialization takes four years of university training.
- Twenty eight (28) physicians have accreditation in Ireland (July 2012).

Capacity of palliative care workforce training in Universities and Medical Schools:

There is no structured approach to palliative care education within undergraduate medical education/training in Ireland's universities. However, it is to be noted that:

- Ireland has six medical schools and six schools of academic nursing
- Medical education is well established at the Royal College of Surgeons Ireland (RCSI), Trinity College Dublin (TCD), University College Dublin (UCD), University College Cork (UCC), University College Galway (UCG), and the University of Limerick (UL).
- A full professorship of palliative medicine was established jointly by TCD, UCD, and Our Lady's Hospice Dublin in 2012.
- A full professorship in palliative care nursing was established jointly by UCD and Our Lady's Hospice Dublin in 2008.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006**Developments/opportunities/barriers relating to the availability of essential medications:**

Readily available.

Developments/opportunities/barriers relating to the accessibility of essential medications:

- Medication is available nationally. Regional models of care have been developed which improve out-of-hours (OOH) services. However, these have not been implemented nationally.
- The Health Service Executive (HSE) has put in place special arrangements for speedy access to medication for palliative care patients under the General Medical Services Scheme (GMS – Medical Card).

Developments/opportunities/barriers relating to the affordability of essential medications:

In Ireland, the State pays for approximately 80% of all medicines. The ultimate cost to the State of medicines dispensed in the community depends on which community medicine scheme the patient uses to access the medicines. Essential medications are covered within these schemes.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There are no legal barriers (and few bureaucratic barriers) to the prescription of opioids or other analgesics in Ireland; there has not been a requirement to change regulations in this area.

Initiatives to promote attitudinal change in relation to 'opiophobia':

None.

Ireland has had specialist accreditation for palliative care physicians since 1995. Accreditation is provided by the Royal College of Physicians of Ireland (RCPI). The specialization takes four years of university training

Initiatives that examine access to opioid medication for economically disadvantaged persons:

- The specific issue of access to opioid medications has not been examined, but the general issue of medication availability has been reviewed.
- The Irish Association for Palliative Care (IAPC) Palliative Care Pharmacists Group has examined this area and has advocated on behalf of economically disadvantaged persons to the Health Service Executive (HSE).
- The Irish Association for Palliative Care (IAPC) Palliative Care Social Work Group has conducted a survey of availability and accessibility to Medical Cards for palliative care patients. In 2012 the findings were used to inform strong, evidence-based advocacy with the Minister for Health on behalf of palliative care patients for simpler process and speedy access to Medical Cards. Through collaboration with the Irish Cancer Society, this advocacy was further extended to include the fast-tracking of Medical Cards for cancer patients.
- The Health Service Executive (HSE) has centralised and streamlined the application process under the General Medical Services Scheme and emergency medical cards are expedited more speedily for palliative care patients and oncology patients.
- There are four principal schemes in Ireland which determine whether people get free or subsidised medicines: (i) General Medical Services Scheme (GMS - Medical Card); (ii) Drug Payment Scheme (DPS); (iii) the Long Term Illness Scheme (LTI); (iv) the Hi-Tech Scheme. Where the patient has a GMS - Medical Card or the medicine is for a specific condition covered by the Long Term Illness (LTI) scheme they do not pay anything, otherwise they pay the first €120 a month of the cost in accordance with the rules of the Drug Payment Scheme (DPS).

Initiatives that consider access to essential medication as a legal and human right:

There is availability and access to essential medication in Ireland. There has been some public debate and support has been given to international initiatives which aim to establish palliative care as a human right, such as the Prague Charter.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- 2010: Palliative Care for Children with Life-Limiting Conditions in Ireland - A National Policy (Department of Health, 2010) This is government policy for the development of paediatric palliative care services in Ireland;
- 2009: Palliative Care Services - Five Year Medium Term Development Framework 2009-2013 (HSE, 2009). This framework details the actions needed and investment required to address the gaps in the provision of palliative care services across Ireland that were identified in the *Baseline Study of Hospice/Specialist Palliative Care Services in Ireland* (Irish Hospice Foundation, 2006), and the *HSE Audit of Palliative Care Service Provision* (HSE 2007). It prioritises the geographical areas to be addressed in terms of provision.
- 2008: Palliative care for all: Integrating Palliative Care into Disease Management Frameworks (HSE and Irish Hospice Foundation, 2008). This report signposts and promotes the delivery of palliative care to those with conditions other than cancer, in all settings and at all levels.
- 2007: HSE Audit of Palliative Care Service Provision (HSE, 2007). This study along with the *Baseline Study on the provision of Hospice/Specialist Palliative Care Services in Ireland* (Irish Hospice Foundation, 2006) highlighted the inequity of access and disparities in the provision of palliative care services across Ireland.

The impact of these policy changes and ways in which they have been important:

- Implementation of the "Palliative Care for Children with Life-Limiting Conditions in Ireland - A National Policy" (2010) has resulted in the appointment of Ireland's first Consultant Paediatrician with a Special Interest in Paediatric Palliative Medicine, and the appointment of eight outreach nurses to support the care of children with life-limiting conditions in the home.

- The Health Service Executive (HSE) has established the multi-stakeholder National Development Committee for Children's Palliative Care which has responsibility for implementation of the recommendations in the "Palliative Care for Children with Life-limiting Conditions - a National Policy". Under the policy the national roll-out of a children's dataset begins in 2013.
- The first children's hospice in Ireland was opened in 2011.
- Implementation of the "Palliative Care - Five Year Medium Term Development Framework 2009 - 2013" is slow and incomplete, due to the economic and budgetary constraints at the HSE. Although some progress in addressing deficits in service provision has been made, significant regional inequities persist.
- The publication of "Palliative care for all: Integrating Palliative Care into Disease Management Frameworks" (HSE and Irish Hospice Foundation, 2008) has been associated with increasing numbers of patients with non-malignant disease receiving palliative care. The document provides an action plan which supports the achievement of this goal.

Development of a national palliative care consensus:

The HSE Palliative Care Programme: developed eligibility and discharge criteria for specialist palliative care services in 2011; developed a glossary of terms for palliative care in 2012; developed the palliative care competency framework (2012), and is currently in the process of developing palliative care clinical practice guidelines, care pathways, and role delineation guidelines.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

The Health Service Executive (HSE) Clinical Strategy and Programmes Directorate has been associated with the development of stakeholder advisory groups (medical, nursing, allied health professionals, management, and patient advocacy forums) which inform the work of the Directorate. Regional and national meetings influence the development of strategy and occur on a regular basis (e.g. monthly or quarterly depending on the stakeholder group).

- The Irish Association for Palliative Care (IAPC), as the professional membership representative body for palliative care professionals in Ireland, advocates regularly in relation to the strategic development of palliative care at the level of the Minister for Health, the Minister for Children, and the Department of Health as well as other relevant government ministers and HSE senior decision-makers.
- The Irish Hospice Foundation (IHF) is an advocacy organisation that works closely with the Health Service Executive (HSE). It regularly commissions and funds joint initiatives with the HSE to promote palliative care and end-of-life care.

Development of an advocacy framework for integrating palliative care into the health care system:

Ireland has a long tradition of advocacy in this area and several groups have operated on a national platform since the 1980s.

- The Joint Advocacy Group for Palliative Care (2006) is an advocacy collaboration between the Irish Association for Palliative Care (IAPC), the Irish Hospice Foundation (IHF), and the Irish Cancer Society (ICS) with the purpose of promoting the palliative care agenda within the overall strategy and policy development of the health service in Ireland.
- The HSE National Development Committee for Children's Palliative Care (2010) is a multi-stakeholder committee that oversees and makes progress on the implementation of the key recommendations of the "Palliative Care for Children with Life-limiting Conditions - a National Policy" (Department of Health and Children, 2010).
- The HSE Palliative Care National Consultative Forum (2012) (Implementation Steering Committee of the "Palliative Care Services - Five Year Medium Term Development Framework" (2009)). The Forum was designed to monitor and present the progress being made on recommendations contained within the Framework and to provide a platform for communication and dialogue on Palliative Care in Ireland.
- The Irish Hospice Foundation established the Forum on End of Life in Ireland (2009) so as to engender greater public discussion about the care of those at the end of their lives. The initiative is also concerned with identifying participants' views about end of life issues, and their wishes and aspirations for the care and treatment they receive. The Health Service Executive (HSE) is represented on the Forum on End of Life National Council.
- The HSE National Advocacy Unit was established in 2012 and palliative care stakeholders have representation.

Strategies to improve political awareness and government recognition of palliative care:

Advocacy strategies by the Irish Hospice Foundation, the Irish Association for Palliative Care, the Irish Cancer Society, and the voluntary hospice movement, all include influencing, lobbying, and building relations with Members of the Oireachtas (the Irish Parliament), and with healthcare policy makers; includes the production of briefing documents and position statements; also includes the involvement of specialist palliative care practitioners and managers in national change management and leadership roles.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

- There is a long history of fundraising in Ireland, particularly through the voluntary hospice movement, that serves to support the development and provision of hospice and palliative care across the country.
- Since 1987 the Irish Cancer Society has funded the free-of-charge Night Nursing Service for patients with cancer who require end-of-life care in their own homes. In 2010, 1500 families availed of the Night Nursing Service in Ireland.
- Since 2007 the Irish Hospice Foundation provides funding to the Irish Cancer Society Night Nursing Service for patients with non-malignant diseases who require end-of-life care in their own homes.
- Voluntary and non-profit organisations such as the Irish Hospice Foundation, Irish Heart Foundation, Alzheimer's Society of Ireland, Chronic Pain Ireland, Irish Motor Neurone Disease Association, as well as the All Ireland Institute of Hospice and Palliative Care, the Health Research Board, and the Irish Association for Palliative Care, provide grants and funding for education and research and service development in palliative care.
- The Atlantic Philanthropies (an international philanthropic body) has provided significant funding to hospices and other stakeholders in palliative care with the objectives to advance palliative care policy, to develop capacity in palliative care, and to further advance the delivery of palliative care services on the island of Ireland.

Involvement with the European Union in relation to hospice and palliative care initiatives:

None.

Development of initiatives framing palliative care as a 'human right':

Support has been given to international initiatives which aim to establish palliative care as a human right.

General legislation relating to palliative care:

Palliative Care in Ireland is a legal entitlement available through the national healthcare system.

Published national documents relating to palliative care standards and norms:

- The *National Quality Standards for Residential Care Settings for Older People in Ireland* (Health Information & Quality Authority, HIQA, 2009) contains a standard on End of Life Care: Standard 16 focuses on End of Life Care: 'Each resident continues to receive care at the end of his/her life which meets his/her physical, emotional, social and spiritual needs and respects his/her dignity and autonomy'.
- The Irish Hospice Foundation - Hospice Friendly Hospitals (HfH) published *Quality Standards for End-of-Life Care in Hospitals* (2010).

National Plan or Strategy of Palliative Care:

- The Report of the National Advisory Committee on Palliative Care (Department of Health, 2001) is the national policy for the provision of palliative care services in Ireland (www.dohc.ie/publications).
- The Palliative Care Services - Five Year/Medium Term Development Framework 2009 - 2013 (HSE, 2009) provides a national strategic template to address and prioritise disparities of palliative care service provision across Ireland.
- Palliative Care for Children with Life-limiting Conditions - A National Policy (2010) is the national plan for the provision of paediatric palliative care in Ireland.

National Cancer Control Strategy:

- Cancer Services in Ireland - a National Strategy (Department of Health, 1996) acknowledged the role of palliative care in improving the quality of life of patients for whom cure was no longer possible, through establishing palliative care in the curricula for nurses, physicians and allied health professionals. It also underlined the requirement for expansion of palliative care services.
- A Strategy for Cancer Control in Ireland (Department of Health, 2006) advised the setting up of a National Cancer Control Programme (established in 2007). The Strategy provides for cancer centres to be networked together in managed cancer control networks. Ireland's eight specialist cancer centres are now located and networked within each of the four Health Service Executive administrative regions (www.allirelandnci.com).

National HIV/AIDS Strategy:

AIDS Strategy 2000: Report of the National AIDS Strategy Committee (Department of Health, 2000).

National Primary Health Care Strategy:

Primary Care - A New Direction (Department of Health, 2001).

Designated policy maker for the delivery of palliative care services:

- Palliative care policy development is under the remit of the Department of Health - the Office for Older People.
- Health Service Executive (HSE) Integrated Services Directorate (ISD) and the HSE Palliative Care Programme share joint responsibility for the strategy, policy, governance, and operations dimensions of Palliative Care delivery within the Health Service Executive (HSE).

Department of Health specific responsibility for the delivery of palliative care services:

The Health Service Executive (HSE) Integrated Services Directorate (ISD) has responsibility for the delivery of palliative care services.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

Palliative Care services submit monthly performance metrics to the Health Service Executive (HSE) and Key Performance Indices are published annually.

Opioid legislation/Pain guidelines:

- Opioid legislation: There is no information available at this time.
- National guidelines on the pharmacological management of cancer pain are to be published in 2013.

Funding of palliative care services:

- Ireland's palliative care service is funded through a combination of government funding and voluntary sector/charitable funds. The annual HSE National Service Plan indicates the budget allocation to palliative care services in overall health service spending in Ireland.
- Patients are not required to pay for palliative care consultation, hospitalisation or medications (although private health insurance can form part of payment for palliative care services).

There is a long history of fundraising in Ireland, particularly through the voluntary hospice movement, that serves to support the development and provision of hospice and palliative care across the country

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

Change in public awareness or perception of hospice and palliative care is difficult to judge as formal research has not been conducted in this area in Ireland. However, experience and anecdotal evidence would suggest: increasing recognition of the role of palliative care at earlier stages of disease management in conjunction with other treatment strategies; increasing recognition of the role of palliative care in management of non-malignant disease; increasing value now placed on palliative care because of improved recognition of effectiveness of pain and symptom management; and provision of psychosocial and spiritual support.

Major public discussion, debate or controversy about hospice and palliative care:

- Assisted suicide/euthanasia is illegal in Ireland. Some cases are being mounted in the Irish Courts to obtain a right to assisted suicide. There is public discussion and debate, particularly in the media, about the place of euthanasia and palliative care in Irish society.
- There has been significant debate about regional inequities in palliative care provision.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

- In June 2008, the 'National Strategy for Service User Involvement in the Irish Health Service' was launched. This Strategy confirms the commitment of the Department of Health and the HSE to provide opportunities for people who use health services and their families and advocates to have input into how services operate and to provide feedback. The HSE Palliative Care Programme engages regularly with the Service User and Consultation Forum.
- The Forum on End-of-Life in Ireland is an Irish Hospice Foundation project which engages with the public on end-of-life issues to find out what people in Ireland believe about dying, death and bereavement and to promote their engagement in this process.
- Individual service providers have engaged with RTE (the national broadcaster) and others to produce a number of documentaries focusing on palliative care service provision or the experience of living with a life-limiting condition or facing death.
- The Irish Association for Palliative Care (IAPC) has published position papers on Voluntary Euthanasia (2011), on Palliative Sedation (2011), and on Artificial Hydration in Terminally Ill Patients (2011).
- To celebrate World Hospice and Palliative Care Day 2011, the Irish Association for Palliative Care (IAPC) produced a video entitled "What is Palliative Care?" (2011) - an initiative designed and produced to raise awareness of palliative care amongst the general public and other health care professionals (available at www.palliativecare.ie and on YouTube.com).
- The All Ireland Institute of Hospice and Palliative Care (AIHPC) has launched Voices4Care (2013) which is an initiative that seeks to influence how palliative care is planned and delivered. Voices4Care is a volunteer group made up of patients (service users), carers or former carers, and people from the wider community. The AIHPC also plans to work closely with service providers, statutory organisations and key social organisations to promote and facilitate public and community understanding of death, dying and loss. Drawing upon the principles of social justice, equity and health for all, the AIHPC will take a population health approach to palliative care issues;
- The Compassionate Communities Project is a health-promoting initiative of a regional specialist palliative care service in the West of Ireland. The project aims to develop ways to support and assist communities, to help groups, families and individuals to cope with the experience of death dying and grief. As a part of this project, Watch House Cross Library has worked in partnership with Milford Care Centre to develop a bibliography section in the library as a resource for people in the community to use during periods of crisis in their lives (such as bereavement).

Hospice or palliative care 'success' stories:

- Since 1987 the Irish Cancer Society has collaborated with Ireland's hospices and the health service to provide the free-of-charge Night Nursing Service for patients with cancer who require end-of-life care in their own homes. In 2010, 1500 families availed of the Night Nursing Service in Ireland. This service frequently manifests the benefits of palliative care and end-of-life care to the public in general and represents partnership between the General Practitioners (GP), the hospice home-care team, community specialist palliative care team and/or the hospital-based specialist palliative care team.
- Since 2007 the Irish Cancer Society (funded by the Irish Hospice Foundation and accessed through community specialist palliative care teams) has provided Night Nursing for patients with non-malignant diseases who require end-of-life care in their own homes.
- 2011: Ireland's first children's hospice – LauraLynn Ireland's Children's Hospice – opened in 2011.
- In 2013 the Irish Association for Palliative Care (IAPC) celebrates 20 years since foundation as Ireland's sole multidisciplinary professional membership organisation for those delivering palliative care or with an interest in palliative care. Today it is the largest representative body of palliative care professionals in Ireland. It continues to adhere to its founding principles of a vibrant sharing and learning network dedicated to delivering a higher level of care through enhancing professional knowledge and furthering expertise. It is recognised by national policy and decision makers as an Expert Voice driving for national policy to provide patient-centred, equitable and accessible palliative care for all who need it. IAPC's founding member and inaugural Chairperson, Dr Tony O'Brien, Consultant Physician in Palliative Medicine, chaired the National Advisory Committee for Palliative Care which produced Ireland's blueprint policy for the delivery of palliative care in Ireland, the Report of the National Advisory Committee on Palliative Care (Department of Health, 2001).
- 2010: The HSE Palliative Care Programme was established in 2010 within the HSE Clinical Strategy and National Clinical Programmes Directorate. This has been a significant achievement for the development of palliative care services in Ireland. The aim of the HSE Palliative Care Programme is to ensure that patients with life-limiting conditions and families can easily access a level of palliative care service that is appropriate to their needs regardless of care setting or diagnosis. Specific objectives of the Palliative Care Programme are to strengthen clinical leadership, to improve clinical performance, and to ensure care is delivered in a manner that maximises quality and efficiency.
- 2012: a strategic approach to the development of palliative care is underpinned by the successful partnership of the HSE Integrated Services Directorate (ISD) and the HSE Palliative Care Programme through taking a joint collaborative approach to the strategy, policy, governance, and operations dimensions of Palliative Care delivery within the HSE.
- 2010: The All Ireland Institute of Hospice and Palliative Care (AIHPC) represents an all island of Ireland (Republic of Ireland and Northern Ireland) palliative care collaboration initiative, comprised of a consortium of five hospices and five universities, supported by voluntary and statutory bodies. Through enhancing the capacity to develop knowledge, promote learning, influence policy and shape practice, the aim is to improve the experience of supportive and palliative end-of-life care on the island of Ireland.
- The work of the Irish Hospice Foundation's "Hospice Friendly Hospitals" (HfH) Programme (2007 -2012) is focused on bringing hospice principles into hospitals practice: making end-of-life care central to hospital care and bringing it 'from the margins to the mainstream of health services'. A number of initiatives have been developed by the HfH programme including: the Design & Dignity Challenge Fund to assist building projects aimed at enhancing the dignity of people who die in Irish hospitals (and that of their families); practice development programmes; development of a national audit tool for end of life care; development of a communications training programme.

Initiatives seeking the legalisation of euthanasia or assisted dying:

International organisations such as Dignitas promote debate about this topic but to date there have not been any national initiatives to amend current legislation.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

- Ireland is fortunate in that it has developed a highly skilled body of specialist palliative care practitioners who are keenly motivated to continue to improve the quality of care provided to patients and their families with life-limiting conditions and to ensure that palliative care is available on an equitable basis to all those who require it.
- The palliative care community has developed strong partnerships between national and international specialist and generalist practitioners and recognises the value of collaboration in achieving these goals. The future is bright when the depth and breadth of expertise available to further develop palliative care services is considered. This optimism is tempered, however, by national economic challenges.

Most significant issues facing hospice and palliative care in the next three years:

The national health service reform process will demand a strategic response from the palliative care sector that will:

- articulate clearly the specialist and generalist models of palliative care
- develop guidelines and pathways that support the delivery of high quality of care in all settings and for all populations
- provide ongoing quality improvement initiatives
- develop measures that capture structure/process and outcomes of care that demonstrate cost-effectiveness and the value-for-money of palliative care
- deliver on prospective funding requirements.

Implications for palliative care relating to the current economic crisis:

The future development of palliative care services in Ireland, including addressing inequity of access and availability of services across geographic regions, will be critically affected by Government focus and Health Service Executive (HSE) performance. There is clear indication that palliative care service deficits will have to be addressed through the achievement of service efficiencies or redeployment of resources.

Ireland is fortunate in that it has developed a highly skilled body of specialist palliative care practitioners who are keenly motivated to continue to improve the quality of care provided to patients and their families with life-limiting conditions and to ensure that palliative care is available on an equitable basis to all those who require it

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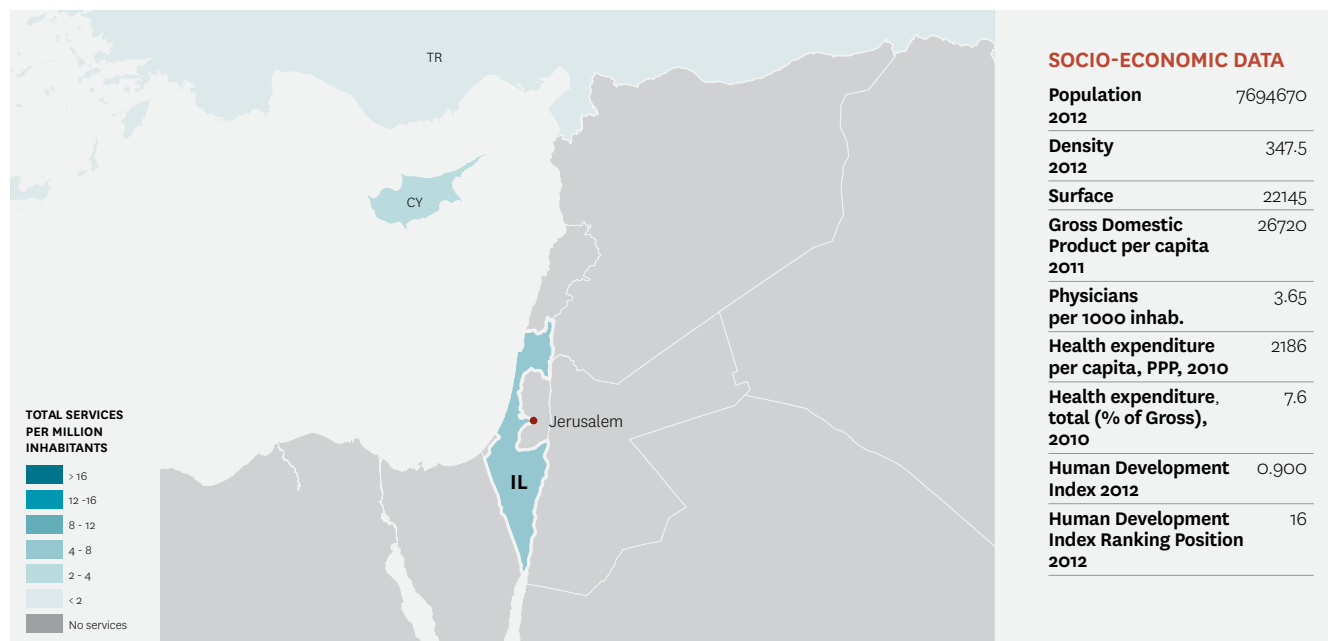
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 0 (15) |
| Hospital palliative care support team | 3 (n/a) |
| Home palliative care support team | 20 (n/a) |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 3 (30) |
| Palliative care units in non-tertiary hospitals | 5 (100) |
| Inpatient hospice | 2 (32) |
| Day hospice/day care centre | 0 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Israel Palliative Medicine Society
- Israel Association of Palliative Care

Additional comments:

- Part of home care services includes home care cancer services that also deliver home palliative care to. In 2010, a home hospice organization was set up as a private initiative. This initiative subsequently signed agreements with all of the national health care providing organizations as a sub-contract for the provision of home hospice and palliative care services. This means that now in theory at least home hospice and palliative care services are available county wide, free of charge to anyone in need. At the present time 160 patients are being cared for at home throughout the country.
- Number of home palliative care teams is an estimate only.
- Home care services include home care cancer services that deliver home palliative care.
- Number of beds allocated to hospices is an estimate only.
- Although no palliative care beds are specifically allocated to the chronically ill in nursing homes, many nursing homes provide these services.
- Bereavement support is not well developed in hospice or palliative care services.

Palliative care services for children:

There is one paediatric palliative care unit in a tertiary hospital; one paediatric inpatient hospice; and six paediatric hospital palliative care support teams. There is only one hospital with a purpose built paediatric hospice. However, that hospice no longer has a dedicated palliative care specialist. Other paediatric hospitals offer some form of palliative care home services.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|------|---|
| 1996 | A prescription law ("Changes in opioid prescription regulation") is passed that allows opioids to be prescribed at one month intervals and that removes maximal dose limitations and allows "as needed" dosing. |
| 1998 | Tel Aviv University recognizes the need to teach palliative care and introduces a 400 hours course including clinical practice and a Diploma |
| 2001 | Ben Gurion University recognizes the need to teach palliative care and introduces a short introductory course (40 hours). |
| 2004 | Tel Aviv University recognises the need to teach palliative care and introduces a short introductory course. |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- A Commission was created by the Ministry of Health concerning the organization of palliative care services;
- In 2009, the Ministry of Health requested hospitals and sickness funds to create palliative care beds in every hospital and nursing home and to provide palliative care for patients at home.
- 2009: Tel Aviv University introduces in VI year an elective two-week rotation in Tel HaShomer Palliative Care Department.
- 2013: A commission was created by the Ministry of Health to develop palliative care in nursing homes.

Overall progress in hospice and palliative care:

Hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: No more palliative care beds have been created but there is more awareness about the necessity for palliative care;
- Nursing homes: There is more awareness and in 2013 palliative care will begin to be provided in these settings (palliative care beds will be created);
- Residential homes for the elderly: As above;
- Other community settings: There is an increase in the number of services providing home-based palliative care.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

There has been a very slight expansion in addressing the needs of 'non-cancer' patients.

Perceived barriers to the development of hospice and palliative care:

- Funding;
- Organizational barriers;
- Not a recognized specialty.

Perceived opportunities for the development of hospice and palliative care:

- Specialty recognition;
- Supervision and teaching of newly created palliative care teams;
- Introduction of academic teaching of palliative medicine (undergraduate and post-graduate) in other schools of medicine (it is already taught at Tel Aviv University).

Other issues relevant to the development of hospice and palliative care:

- An important issue was The Law of the Dying where palliative care was noted as an option for patients who refuse to be treated or to continue with curative treatment;
- The Ministry of Health decision to organize palliative care services at home and to improve the inpatient service;
- The recognition of palliative care as a nursing specialty; for physicians the process of recognition is more difficult (the process began four years ago and to date there has not been a final decision made about it).
- The recognition of Palliative Medicine as a medical sub-specialty.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- Israel Palliative Medical Society.
- "Tmicha" the Israel Association for Palliative Care (IAPC)

Directory or catalogue of palliative care services:

There is some information on the IAPC website.

Congresses, scientific meetings or scientific journals in palliative care:

- There is an annual conference organized by an NGO called "Tmicha", attended by several hundred participants.
- There is an annual conference organized by Israel Palliative Medical Society attended by physicians and nurses.
- There is an annual conference organized by Israel Association of Palliative Care attended by several different team members.

Palliative care research capacity:

There is some research but there is a need for development in this area.

Palliative care collaboration:

- Hospice Upper Galilee has an informal twinning arrangement with Rowans Hospice in Portsmouth, England. This hospice has sent representatives to Israel on two occasions and one Israeli delegation has visited England.
- INPACT is a nationwide collaborative effort that has been running for several years; a team of physicians, nurses and social workers were trained to teach an entry level course in palliative care.
- The Israel Cancer Association promotes activities to celebrate World Hospice and Palliative Care Day.
- The Palliative Care Department at Sheba Medical Centre has a strong collaboration with all palliative home-care teams throughout the country.
- The Palliative Care Department at Sheba Medical Centre has a strong collaboration with Tel Aviv School of Medicine.
- In 2013, a process of collaboration began between the Palliative Care Department at Sheba Medical Centre, Carol Davila Faculty of Medicine, Bucharest, Romania and King George Faculty of Medicine, London, UK.

Worldwide palliative care alliance level of development:

Group 2 (capacity-building activity).

A private home care initiative was established in conjunction with the Ministry of Health (MOH). Inpatient services have improved and palliative care provided in some nursing homes. There has been a slight expansion in addressing the needs of 'non-cancer' patients

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- 1998: A postgraduate curriculum in palliative care was developed at Tel Aviv University;
- 2004: There has been some development in the undergraduate teaching of palliative care. Medical students were taught palliative care on three occasions during their studies; once during basic teaching, once during a visit to a palliative care unit and a third time during two weeks of palliative care teaching in the sixth year (at Tel Aviv University); the clinical teaching takes place at the Palliative Care Department at Sheba Medical Center
- There are short introductory courses of palliative care for teams in every part of the country (INPACT_40 hours duration).
- Initiatives in different hospitals have organized short courses of palliative care.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: As above;
- Nursing: There are some hours of palliative care teaching during nursing studies; the nursing specialty in palliative care is now recognised;
- Social work: Social workers can participate in the 40 hour course mentioned above;
- Other professions: There is no information available at this time.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: There is a postgraduate course in palliative care (400 hours study and two weeks practical training) at Tel Aviv University
- Nursing: There are some hours of palliative care teaching during oncological postgraduate courses; the nursing specialty in palliative care is now recognised;
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Translation of palliative care documents or other materials:

Palliative Care for Children has been translated. However, it is not necessary to translate materials because most documents are circulated in English.

Initiatives to develop healthcare professional leadership in palliative care:

The Israel Palliative Medical Society pioneered the development of palliative care as a medical Specialty.

Officially recognized medical certification:

- Palliative care was recognized as a clinical sub-specialty for physicians by the National Medical Scientific Council in 2012.
- Diploma post-graduate course at Tel Aviv School of Medicine.

Capacity of palliative care workforce training in Universities and Medical Schools:

There is no information available at this time.

Developments/opportunities/barriers relating to the affordability of essential medications:

No problems relating to the affordability of essential medications.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

There have been a lot of conferences about pain control and the use of opioids.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

In Israel there is no problem – all oncological patients receive opioids at no cost.

Initiatives that consider access to essential medication as a legal and human right:

No initiatives are necessary because access to essential medication is already recognised as a legal and human right.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- The Terminally Ill Law;
- The Directive of the Ministry of Health.

The impact of these policy changes and ways in which they have been important:

- There is more awareness about palliative care as a humanistic form of treatment at the end of life;
- Patients now have the right to choose what form of treatment they prefer; aggressive treatment against the illness until the end of life - or palliative care;
- Patients now have the right to choose their place of death;
- There are more efforts to create specialized palliative care teams/beds;
- Palliative care is now recognized as a specialty in nursing;
- Palliative care is now recognized as a Medical Sub Specialty.

Development of a national palliative care consensus:

- The Israel Palliative Medical Society organized the two-years postgraduate course in palliative medicine at Tel Aviv University;
- The Israel Palliative Medical Society has developed Clinical Guidelines of Palliative Care;
- The Israel Palliative Medical Society made great efforts to develop palliative medicine as a sub-specialty.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

No problems relating to the availability of essential medications.

Developments/opportunities/barriers relating to the accessibility of essential medications:

No problems relating to the accessibility of essential medications.

A Commission was created by the MOH on the organization of palliative care services requesting hospitals and sickness funds to provide palliative care in every hospital and nursing home and at home. There is more awareness about palliative care

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

Meetings have taken place with the Minister of Health (and also with some deputies) to develop palliative care strategies (the process continues).

Development of an advocacy framework for integrating palliative care into the health care system:

A Commission was created to recommend the integration of palliative care services into the health care system.

Strategies to improve political awareness and government recognition of palliative care:

- Meetings with the Ministry of Health and other political personalities;
- The Israel Palliative Medical Society organized scientific meetings and invited policy makers to attend;
- Policy makers were invited to visit palliative care departments;
- Different journal publications and TV programmes have been used to improve political awareness and government recognition of palliative care.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

There was a large donation from a Jewish organization to create a home-based palliative care service.

Involvement with the European Union in relation to hospice and palliative care initiatives:

The General Director of the Ministry of Health and the Israel Cancer Association General Director participated in September 2011 at an EU meeting (but no information about the meeting is available).

Development of initiatives framing palliative care as a ‘human right’:

The organization of the Ministry of Health Commission on Palliative Care.

General legislation relating to palliative care:

The National Health Law guarantees all residents of the country care “from the cradle to the grave”. In addition, there is a Ministry of Health paper delineating what the provision of palliative care means for hospitals, communities and nursing homes (to be implemented by 2013).

Published national documents relating to palliative care standards and norms:

Israel Palliative Care Medical Society is going to publish Clinical Guidelines for Palliative Care.

National Plan or Strategy of Palliative Care:

There is no information available at this time.

National Cancer Control Strategy:

There is no information available at this time.

National HIV/AIDS Strategy:

There is no information available at this time.

National Primary Health Care Strategy:

There is no information available at this time.

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

There is no information available at this time.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- There are clear laws which make opioids (including the latest ones) available by prescription; they are free for cancer patients; the opioid prescriptions are more difficult to complete than non-opioid ones. Opioids can usually be obtained immediately or ordered relatively quickly if an unusual opioid or large dose.
- There are printed pain guidelines available.

Funding of palliative care services:

- There is no payment required for palliative care consultation, hospitalisation or medication;
- The provision of palliative care in Israel is patchy and there are a few areas where proper care cannot be obtained through public means. In addition, Israel is a country where private services are provided alongside public ones, so if a family is not satisfied with the care they receive, some will turn to private providers. However, where hospices serve the population no one resorts to private sources;
- There are two private home palliative care units;
- At present almost all palliative care is provided for terminal cancer patients.

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006**Change in public awareness or perception of hospice and palliative care:**

There has been a slight change in public awareness of hospice and palliative care (but people are still afraid of the terms).

Major public discussion, debate or controversy about hospice and palliative care:

No major public debate, but there have been a number of publications in different journals and some television discussions.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

Publications in journals and sometimes TV broadcasts have broadened awareness and understanding of hospice and palliative care.

Hospice or palliative care ‘success’ stories:

- Hospice Upper Galilee sent a patient home after four months in the hospice and she survived for a further two years; she received home care and the hospice was in continuous contact with her throughout this time;
- In 2012, a couple celebrated their “silver wedding” at Hospice Upper Galilee; the event was published by one of the most popular journals in the country.

Initiatives seeking the legalisation of euthanasia or assisted dying:

- A tentative attempt to pass legalisation about physician-assisted suicide through the Israeli parliament was unsuccessful.
- Israel Palliative Medical Society presented its position against euthanasia and assisted suicide on television and radio and in journals.

The Law of the Dying was passed; palliative care was noted as an option for patients refusing to be treated. Palliative Medicine has been recognised as a medical sub-specialty and Tel Aviv University have introduced an elective palliative care course

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

There is a good basis for development of home care and in a couple of years there should be a good palliative care network; hopefully the number of in-patients beds will increase and palliative care can also be provided in each nursing home.

Most significant issues facing hospice and palliative care in the next three years:

- Medical specialty recognition;
- Written palliative care standards;
- Organize a Commission to supervise and support newly-created palliative care teams.

Implications for palliative care relating to the current economic crisis:

The Ministry of Health will not approve additional palliative care funding.

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Italy¹

NATIONAL ASSOCIATION

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 0 |
| Home palliative care support team | 312 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 0 |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 175 (1991) |
| Day hospice/day care centre | 0 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- "Le Cure Palliative domiciliari in Italia", Quaderni di Monitor 2010, 26 Suppl (for home palliative care support teams) (http://www.salute.gov.it/imgs/C_17_pubblicazioni_1452_allegato.pdf)
- "Hospice in Italia 2010 Seconda rilevazione ufficiale" (published by Società Italiana di Cure Palliative, in collaboration with Fondazione Floriani e Fondazione Isabella Seragnoli): (http://www.salute.gov.it/imgs/C_17_pubblicazioni_1450_allegato.pdf)

Additional comments:

- Approximately 53.7% of the workforce in palliative care is full-time. However, not all of the home palliative care support teams operate on this basis.
- 82 (47%) inpatient hospices are situated in hospitals; 93 (53%) inpatient hospices are freestanding units.

Palliative care services for children:

There are eight paediatric home palliative care support teams, and two paediatric inpatient hospices (six beds).

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|-------------|---|
| 2001 | The law on opioid prescription is passed. |
| 2004 | The Italian Association of Palliative Care marks the publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organization of palliative care) by translating the document ready for publication and dissemination. |
| 2005 | All opioids for strong and moderate pain are made reimbursable by the public health care system (including oxycodone, oxycodone, methadone, codeine, tramadol, morphine, fentanyl and buprenorphine patches). |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- In Italy, the most significant change since 2006 has been the approval, by the Italian Parliament, of the first National Law of Palliative Care (N.38/March 2010). In the first article, the Law establishes that palliative care is a fundamental right for all Italian people and that all local health services have the duty to implement palliative care networks to guarantee this right. The law establishes that, in every region, there will be two separate but integrated networks – a palliative care network and a pain therapy network. The law also describes standards for the accreditation of services and the professional requirements for doctors and nurses to work in palliative care teams. The Law establishes that each year the Ministry of Health has to present a report about the development of palliative care networks and pain therapy networks in different Italian regions to the Italian Parliament.
- Subsequent official agreements between national government and regions (December 2010 and July 2012) define the guidelines for the development and organization of regional and local palliative care networks
- The process to formally approve the discipline of palliative care is almost completed.

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: Since 2006, there has been a significant growth of palliative care support teams in Italian hospitals (but it is not possible to provide an estimation of this growth);
- Nursing homes: This is a setting where palliative care has not been sufficiently developed. There are some local initiatives in this area but they are not very widespread.
- Residential homes for the elderly: The same situation as in nursing homes;
- Other community settings: There is no information available at this time.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

There has been a positive development in this area, mainly in addressing the needs of neurological patients. In 2011, the Italian Society of Palliative Care (in collaboration with scientific societies and patient associations), produced a consensus document about palliative care for patients with ALS. During the National Palliative Care Congress in 2010, palliative care for patients with ALS was one of the major topics of discussion.

Perceived barriers to the development of hospice and palliative care:

- There are differences in regional laws about the features and development of regional palliative care networks. The National Law N.38/2010 attempts to reconcile these differences, but a lot of work has still yet to be done. The Italian Constitution establishes that each region can autonomously organise its own regional health service.
- Cultural barriers to the use of strong opioids (mainly morphine) for pain control; educational gaps for many physicians relating to the use of strong opioids for pain control.
- Cultural barriers in Italian society – for example, speaking openly about death and dying and end-of-life care issues.

Perceived opportunities for the development of hospice and palliative care:

- The content of the Law 38/2010.
- To increase the number of inpatient hospices and home palliative care services in Italy.
- To increase the number of professionals (physicians, nurses, psychologists, etc) involved in the provision of palliative care services.

Other issues relevant to the development of hospice and palliative care:

- There is a need to improve communication about prognosis and end-of-life care issues between physicians and patients in advanced stages of illness.
- The transition from curative care to palliative care.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- The Italian Society of Palliative Care (Società Italiana Cure Palliative (SICP)) was formed in 1986; it has a website (www.sicp.it) and is representative of the whole country. In the last three years, SICP has reorganized and renewed its Scientific Journal ("Rivista Italiana di Cure Palliative") and its official website; it also releases a monthly Newsletter.
- The Italian Federation of Palliative Care (Federazione Italiana Cure Palliative (Fed-CP)) is a network of non-profit organizations involved in palliative care formed in 1999; it has a website (www.fedcp.org) and is representative of the whole country.

Directory or catalogue of palliative care services:

- Printed version: "Le Cure Palliative domiciliari in Italia", Quaderni di Monitor 2010, 26 Suppl. (First edition 2010).
- Online version: http://www.salute.gov.it/imgs/C_17_pubblicazioni_1452_allegato.pdf

Congresses, scientific meetings or scientific journals in palliative care:

- The National Congress of the Italian Society of Palliative Care (SICP) is held annually; the congress was held in Trieste in October 2011 and in Turin in October 2012 and was attended by approximately 1500 people on each occasion.
- The journal *Rivista Italiana di Cure Palliative* (RICP) is published four times per year (it has no database index).

Palliative care research capacity:

- There are a number of palliative care research centres in Italy.
- There are a number of palliative care researchers in Italy, including: Augusto Caraceni (<http://www.istitutotumori.mi.it/istituto/istituto/curepalliative.asp>); Marco Maltoni (<http://www.ausl.flo.it/Default.aspx?tabid=755>); Massimo Costantini (http://www.istge.it/dip_epp/cu_pa/costanti.htm).

Palliative care collaboration:

- Some Italian Foundations (Fondazione Floriani, Fondazione Maruzza Lefebvre D'Ovidio, Fondazione Seragnoli, SAMOT and many others) actively participate in many initiatives and events to promote palliative care in Italy.
- World Hospice and Palliative Care Day is celebrated in many different regions/areas of Italy; there are volunteer events organized by various hospice and home palliative care charities.

Worldwide palliative care alliance level of development:

4B (Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

There is no information available at this time.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Sporadic palliative care education in certain courses (but this is not consistent).
- Nursing: Same as Medicine.
- Social work: No developments.
- Other professions: No developments.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: According to the Law n.38/10, the National Health Organization is to define the discipline and provide palliative care educational programs.
- Nursing: Same as for Medicine
- Social work: No developments
- Other professions: For psychologists - same as for Medicine

Translation of palliative care documents or other materials:

"EAPC - Guidelines for the development of nurse education in palliative care" (2008).

Initiatives to develop healthcare professional leadership in palliative care:

SICP organizes workshops with regional leaders in palliative care to develop professional leadership.

Officially recognized medical certification:

Since April 2012, there has been a Master's degree in Italy entitled "Master Universitario di Alta Formazione e Qualificazione in Cure Palliative per medici specialisti". The Master's degree consists of 1500 hours classroom teaching and 1500 hours practical training (inpatient unit/hospice/home care/consultation).

Capacity of palliative care workforce training in Universities and Medical Schools:

- There are 40 medical schools in Italy, but it is not known whether palliative medicine is a mandatory, optional or other component;
- There are two full professors of palliative medicine (other category).
- There is also one "other professor" of palliative medicine.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

The Law 38/2010 established new rules (more simplified) about the availability and accessibility of essential medications for palliative care; the rules mainly relate to the prescribing and dispensing of opioids for pain relief.

Developments/opportunities/barriers relating to the accessibility of essential medications:

There is no information available at this time.

Developments/opportunities/barriers relating to the affordability of essential medications:

There is no information available at this time.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

The new Law promotes regional initiatives that inform public opinion about palliative care and the opportunities available for the maximum control of pain. Many educational initiatives have been developed around these themes (including "opiophobia") and at various levels (hospital, home care in collaboration with GPs and scientific societies, nursing homes, etc).

Initiatives that examine access to opioid medication for economically disadvantaged persons:

All opioid medications in Italy are free of charge for patients.

Initiatives that consider access to essential medication as a legal and human right:

The Italian Law 38/2010 addresses the rights of terminal patients to dignity and autonomy and promotes support for the family.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

The Italian Law 38/2010:

- establishes the obligation to assess and treat the pain of every terminally-ill patient.
- introduces legislation relating to paediatric palliative care services.

The impact of these policy changes and ways in which they have been important:

- The changes are in progress, and it is hoped that there will be significant improvement in the availability of palliative care in many Italian regions in the near future.
- There is a representative of SICP in 20 regions of Italy.

Development of a national palliative care consensus:

The new Law establishes organisational standards for the local palliative care networks and it is anticipated that this will have a positive impact for the development of these networks.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

Each year, SICP organises a National Conference, with the participation of more than 1,500 physicians, nurses, psychologists, social workers etc. During the conference, meetings are organised that are specifically dedicated to promote collaboration between different stakeholders and policy makers (NGOs, Ministry of Health, other scientific societies - in particular involving GPs, etc.) Previous National Conferences were organised in Lecce (2009), Rome (2010), Trieste (2011) and Turin (2012).

Development of an advocacy framework for integrating palliative care into the health care system:

SICP collaborates with FedCP (a federation representing many NGOs providing palliative care). During recent years, the collaboration between these two organisations has greatly improved, and together they have promoted the integration of palliative care into the Italian National Health System. One of the main results of this collaboration was the approval of the Italian Law 38/2010; there has also been improved collaboration between SICP and other medical societies.

Strategies to improve political awareness and government recognition of palliative care:

SICP actively participates in the National Commission of Palliative Care and in the organization of the National Health Program; the organisation also collaborates with Age.Na.S, the National Agency for Regional Health Services.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

The Law 38/2010 established special funding for the development of palliative care and pain therapy in Italy (not a large amount of money, but nevertheless significant). Many NGOs in Italy and the development of palliative care in the country are supported by private funding.

Involvement with the European Union in relation to hospice and palliative care initiatives:

- SICP and FedCP are collective members of the European Association of Palliative Care (EAPC) and participate in many initiatives of the Association at the European level.
- Since 2006, a number of Italian palliative care organisations have been involved in research projects financed by the European Union.

Development of initiatives framing palliative care as a ‘human right’:

- The Law 38/2010 establishes that palliative care is a fundamental right for all Italian people and that all local health services have the duty to implement palliative care networks to guarantee this right.
- Articles in health publications from the SICP have framed palliative care as a ‘human right’.

General legislation relating to palliative care:

National Italian Law N.38, 2010.

Published national documents relating to palliative care standards and norms:

- Decreto Ministeriale N.43, 22 (Feb 2007): “Definizione degli standard relativi all’assistenza ai malati terminali in trattamento palliativo”.
- Accordo della Conferenza Stato-Regioni (16 Dec 2010): “Linee guida per la promozione, lo sviluppo e il coordinamento degli interventi regionali nell’ambito della Rete di Cure Palliative e della Rete di Terapia del dolore”.
- Intesa della Conferenza Stato-Regioni (25 Jul 2012): “Definizione dei requisiti minimi e delle modalità organizzative necessari per l’accreditamento delle strutture di assistenza ai malati in fase terminale e delle unità di cure palliative e della terapia del dolore”.

National Plan or Strategy of Palliative Care:

Law n. 38, 15/3/2010 “Disposizioni per garantire l’accesso alle cure palliative e alla terapia del dolore”.

National Cancer Control Strategy:

The Italian National Health System describes healthcare provision for cancer patients; it includes the provision of palliative care: “Piano Oncologico Nazionale 2010-2012”:

http://pcbat1.mi.infn.it/~battisti/infn-med/piano_oncologico.pdf;
http://www.salute.gov.it/imgs/C_17_primopianoNuovo_264_documenti_itemDocumenti_o_fileDocumento.pdf.

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy in Italy.

National Primary Health Care Strategy:

There is a National Primary Health Care Strategy in Italy.

Designated policy maker for the delivery of palliative care services:

Following introduction of the Law 38/2010, the Italian Ministry of Health has been designated an Office that is dedicated to supervise the development of regional palliative care networks (and control the quality of their activities) and monitor opioid consumption.

Department of Health specific responsibility for the delivery of palliative care services:

The Department of Health has specific responsibility for the delivery of palliative care services in Italy.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

In Italy, regional governments have responsibility for verifying and controlling the standards of local palliative care activities.

Opioid legislation/Pain guidelines:

- Under Italian Law N.38/2010, a “special” prescription is required only for strong opioids (morphine etc) for parenteral injections and for methadone. No “special” prescription is required for other opioids or patches, etc.
- All opioids are free of charge for patients.
- All strong opioids are available in each pharmacy.
- Pain guidelines are available online at:
<http://www.aiom.it/Attivit%EO+Scientifica/Linee+guida/Terapia+del+dolore+in+Oncologia/1,3494.o./40/>
http://www.salute.gov.it/imgs/C_17_pubblicazioni_1257_allegato.pdf.
http://www.salute.gov.it/imgs/C_17_pubblicazioni_1256_allegato.pdf.

Funding of palliative care services:

- There is no payment for palliative care consultation, hospitalisation or medications.
- Every year, the National Department of Health assigns funds to support special health programs to Italian regional administrations (the amount may change each year): amongst these funds are ones dedicated to the development of palliative care networks.

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006**Change in public awareness or perception of hospice and palliative care:**

- The approval of the new Law by the Italian Parliament has promoted better public awareness about palliative care and about the care of the dying in general in Italy. Many articles have been published in national and local newspapers about this Law.
- Meetings organized by SICP for health care professionals (as well as volunteers etc.) have contributed to increasing awareness and perception of hospice and palliative care.

Major public discussion, debate or controversy about hospice and palliative care:

In recent years, the palliative care movement has been involved in discussion about the government proposal of a new law regarding the topic of “advance directives”. The text of that proposal is very controversial and, in the vast majority of cases, has been viewed negatively by palliative care professionals. With the new political evolution in Italy, discussion about this law has ended.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

Many media initiatives that seek to broaden awareness and understanding of hospice and palliative care have been implemented since 2006 - particularly after 2010 and the approval of the new Law.

Hospice or palliative care ‘success’ stories:

There is no information available at this time.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is no information available at this time.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

- The future of hospice and palliative care development in Italy is positive: the new Law 38/2010 is an important contribution to this positive evolution. The main problem at the moment is the economic crisis; it has created some doubts about the future development of the National Health System in Italy.
- The next step after the enactment of Law 38/2010 is the further development of the discipline and palliative care programs (fellowships).

Most significant issues facing hospice and palliative care in the next three years:

The most significant issues facing palliative care in Italy are the homogeneous development of palliative care networks at different regional levels and the development of palliative care education at all levels (undergraduate and postgraduate).

Implications for palliative care relating to the current economic crisis:

- The challenges will not only be for palliative care but for the economic sustainability of the whole of the Italian National Health System.
- The next significant challenge is the development of home palliative care programs for terminally-ill patients (with all disease types) in all regions of Italy.

There has been a significant growth of palliative care support teams in Italian hospitals. There has also been positive development in providing palliative care for 'non-cancer' patients, in particular neurological patients

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Kazakshtan¹

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 0 |
| Home palliative care support team | 1 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 0 |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 5 (240) |
| Day hospice/day care centre | 0 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

Personal estimates/estimates provided by experts.

Additional comments:

- There are currently five organizations providing inpatient palliative care in five areas of Kazakhstan – Almaty, Pavlodar, Karaganda, Ust-Kamenogorsk, and Kostanai; there is also one organization providing home-based palliative care in Semei.
- Almaty Center for Palliative Care has 100 inpatient beds. There are approximately 175 people employed at the Center, including ten physicians, and 63 'nurse aids'. There is also one lawyer, one social worker, two chaplains and a number of volunteers from religious organizations.

- Inpatient palliative care is provided at the Nursing Hospital, Department of Hospice Red Crescent Society, Karaganda. There are a total of fifty inpatient beds at the nursing hospital; thirty beds are in the Nursing Department and twenty beds are in the hospice. There are approximately forty people employed at the nursing hospital, including seven physicians, eight nurses and twenty two 'nurse aids'.
- Kostanai Palliative Care Department has fifteen inpatient beds. There are approximately eighteen people employed in the department; one physician (Head of Department), seven nurses, nine 'nurse aids', and one chaplain.
- Pavlodar hospice has a total of 15 inpatient beds. There are approximately 19 people employed at the hospice, including two physicians (one 'therapeutic physician' and one psychiatrist), five nurses, one Chief Nurse, five 'nurse aids', two volunteers and four administrators.
- Ust-Kamenogorsk Hospice provides inpatient palliative care; it has a total of 60 beds (20 located in the hospice and 40 located in the nursing hospital). There are approximately 28 people employed at the hospice; 11 physicians (including a psychiatrist, oncologist and a 'physician therapist'), 12 nurses, one social worker, two chaplains and two volunteers.
- Hospice/Charity Service Social Fund, Semei offers home-based palliative care only. The service employs approximately three to four people (one part time physician and two to three nurses).

Palliative care services for children:

Most palliative care for children still occurs at home in Kazakhstan, although some paediatric palliative care provision is available at Almaty Center for Palliative Care. The hospice operates with a multidisciplinary team including a psychologist, doctors, nurses, and volunteers.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

- 2003** The first round-table discussion takes place in Almaty. It is dedicated to the problems of hospice/palliative care development in Kazakhstan. Representatives of Kazakhstani, Russian, and Polish hospices, Kazakhstani Public Health Ministry, World Health Organization, international charitable organizations, and chief doctors of hospitals take part.

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

There has been cooperation between the Kazakhstan school of public health and public association "Credo" with the financial support of Soros-Kazakhstan; this has produced research about the situation of palliative care in Kazakhstan, the results of which were reported to the Ministry of Health. As a result of this initiative, the government included the strategy of development of palliative care into the program of development of health care.

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has remained the same.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: There is no information available at this time.
- Nursing homes: There is no information available at this time.
- Residential homes for the elderly: There is no information available at this time.
- Other community settings: There is no information available at this time.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

There is no information available at this time.

Perceived barriers to the development of hospice and palliative care:

- Low awareness amongst the population about palliative care.
- Passivity amongst government agencies, the medical community, public organizations, and the population, in relation to creating a system of palliative care in the country.
- The lack of decent financial support from the government for the construction of hospices and centres of palliative care.

Perceived opportunities for the development of hospice and palliative care:

- Organization of hospice at home and multidisciplinary teams.
- Training of specialists in palliative medicine.
- Creating centres of palliative care.

Other issues relevant to the development of hospice and palliative care:

In December 2011 in the city of Karaganda, the first republican scientific-practical conference on the problem of development of palliative medicine in Kazakhstan was held; this was a joint initiative from NGO "Credo" and the Department of Oncology at Karaganda State Medical University. The conference attracted experts from Poland, and a resolution was adopted for submission to the Ministry of Health for the postgraduate training of specialists in palliative medicine.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

It is anticipated that a National Association of Palliative Care will be formed in 2013.

Directory or catalogue of palliative care services:

It is anticipated that a catalogue of palliative care services will be produced in 2013 (all the materials are in the stage of development).

Congresses, scientific meetings or scientific journals in palliative care:

The international scientific-practical conference "Problems in the Development of Palliative Care in the Republic of Kazakhstan" (organized by NGO "Credo" and Karaganda State Medical University in 2011) has been held only once and attracted approximately 450 participants.

Palliative care research capacity:

- Kazakhstan School of Public Health, Almaty.
- Karaganda State Medical University.
- Republican Center for the Development of Health Care, Astana.
- Kazakh Scientific and Research Institute of Oncology and Radiology, Almaty.

Palliative care collaboration:

- Soros Foundation (Kazakhstan).
- The Open Society Foundation Public Health Program International Palliative Care Initiative (IPCI).
- NGO "Credo" has collaborated with Lodz Hospice Association (Poland).
- National HIV/AIDS Center, Almaty.
- National Tuberculosis Center, Almaty.
- Almaty Center for Palliative Care.

Worldwide palliative care alliance level of development:

4a (Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision).

Research about the situation of palliative care in Kazakhstan was reported to the Ministry of Health (MOH); as a result, the government included the strategy of development of palliative care into the National Programme for Health Development (2011- 2015)

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:
Palliative care training has been included in the study plans of medical colleges and medical universities.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Students of medical universities are undergoing professional training in hospices.
- Nursing: Students of medical colleges are undergoing professional training in hospices.
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: Courses of advanced training in palliative medicine have been organised and initiated.
- Nursing: There is no information available at this time.
- Social work: There have been some social work initiatives provided by NGOs.
- Other professions: There is no information available at this time.

Translation of palliative care documents or other materials:

International palliative care standards have been translated since 2003; various other guidelines, manuals and other literature have also been translated.

Initiatives to develop healthcare professional leadership in palliative care:

There is no information available at this time.

Officially recognized medical certification:

There is no information available at this time.

Capacity of palliative care workforce training in Universities and Medical Schools:

- There are six medical schools in Kazakhstan (source: National Survey). It is not known how many offer palliative medicine as a mandatory or optional component.
- Karaganda State University has begun to develop a curriculum of palliative medicine.
- There are no Professors of Palliative Medicine in Kazakhstan.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- There are no oral forms of opioids.
- Patch form of opioids were recently registered in Kazakhstan.

Developments/opportunities/barriers relating to the accessibility of essential medications:

- It is a long procedure to prescribe opioids.
- Opioids are available for oncology patients only.

Developments/opportunities/barriers relating to the affordability of essential medications:

Opioids are free of charge for cancer patients.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

There is no information available at this time.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

In 2011, the first republican scientific-practical conference on the development of palliative medicine in Kazakhstan was held; a resolution was adopted for submission to the MOH for the postgraduate training of specialists in palliative medicine

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

A number of legislative acts in Kazakhstan have been adopted; for example, the Code of the Republic of Kazakhstan “On health of people and healthcare system” article 52: palliative care and nursing care. In order to implement the Code of the Republic of Kazakhstan: the Decision of the Government of the Republic of Kazakhstan from November 26, 2009 for №1938 “On approval of the list of categories of the population subjected to palliative care and nursing care”, and Order of the Minister of health of Kazakhstan, dated November 2, 2009 for №632 “On approval of the Rules for palliative care and nursing care” were adopted.

The impact of these policy changes and ways in which they have been important:

- The health of the nation and the development of the health system is the responsibility of the State; this includes the provision of palliative care for the population.
- These policies were important in changing attitudes towards palliative care; they also laid the foundation for the development of palliative care in Kazakhstan. For the first time in an official State document, the concept of palliative care was highlighted.

Development of a national palliative care consensus:

A national palliative care consensus has been developed through legislation, adoption of the National Programme for Health Development (2011- 2015), and the construction of palliative care standards.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

With the financial support of Soros Kazakhstan, the work group of members of the Ministry of Health, the Kazakhstan school of public health, and NGO staff, a national concept relating to the development of palliative medicine in Kazakhstan was created. Part of the proposal was accepted in the program of development of public health and presented at the Congress of Physicians in 2010.

Development of an advocacy framework for integrating palliative care into the health care system:

Palliative care is a part of the public health system.

Strategies to improve political awareness and government recognition of palliative care:

Meetings have been held with the heads of public health services; there have been publications in newspapers and a report highlighting the situation with regard to palliative care in Kazakhstan was submitted to the Ministry of Health.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

The State finances the work of the hospices; Soros Kazakhstan funded the study visits and participation in conferences in Poland, as well as the pilot project “Hospice-at-home” and the training of multi-disciplinary teams in the training centre of Hospice Casa Sperantei in Romania.

Involvement with the European Union in relation to hospice and palliative care initiatives:

There is no information available at this time.

Development of initiatives framing palliative care as a ‘human right’:

The International Health and Human Rights Non-Governmental Organization ‘Aman Saulyk’ have developed initiatives framing palliative care as a ‘human right’.

General legislation relating to palliative care:

The National Health Care Code.

Published national documents relating to palliative care standards and norms:

Palliative care standards and norms are currently under development and will be available in 2013.

National Plan or Strategy of Palliative Care:

There is no information available at this time.

National Cancer Control Strategy:

There is no information available at this time.

National HIV/AIDS Strategy:

There is no information available at this time.

National Primary Health Care Strategy:

The National Programme of Healthcare Development (2011-2015).

Designated policy maker for the delivery of palliative care services:

Republican Center for the Development of Health Care, Astana.

Department of Health specific responsibility for the delivery of palliative care services:

The Department of Health has specific responsibility for the delivery of palliative care services.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- There is a standard process for the prescription and acquisition of opioids in Kazakhstan.
- WHO Recommendations on pain and symptom management have been adopted.

Funding of palliative care services:

No payment is required for palliative care consultation, hospitalization or medication.

Palliative care training has been included in medical universities and nursing colleges. A national palliative care consensus has been developed and public awareness of the need for palliative care has increased

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

- Public awareness of the need for the development of hospice and palliative care has increased.
- Some excellent awareness-raising initiatives are occurring in the country thanks to organizations such as Soros Foundation Kazakhstan.

Major public discussion, debate or controversy about hospice and palliative care:

There is no information available at this time.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

Conferences have been held about the development of palliative care in the Republic of Kazakhstan; there have also been a number of newspaper publications.

Hospice or palliative care 'success' stories:

The pilot project "Hospice at home" (an initiative of NGO "Credo" with the financial support of Soros Kazakhstan) provided palliative care for HIV/AIDS patients in Temirtau, Karaganda region. A home-care team was formed and the members of this team received training in Romania.

Initiatives seeking the legalisation of euthanasia or assisted dying:

Euthanasia or assisted dying is banned in Kazakhstan.

Some excellent awareness-raising initiatives are occurring in the country thanks to organizations such as Soros Foundation Kazakhstan

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

It is hoped that within ten years, hospice and palliative care in Kazakhstan will reach the level of development of many European countries.

Most significant issues facing hospice and palliative care in the next three years:

Joint work on preparing specialists in palliative medicine at the pre-diploma and postgraduate level; this will require direct participation, the training of multi-disciplinary teams to work with the mass-media to attract attention towards palliative care and the development of philanthropy in Kazakhstan society; for example, assistance from private businesses and individuals to assist with the construction of hospices in the country.

Implications for palliative care relating to the current economic crisis:

Funding cuts may result in an inability to expand the network of hospices in Kazakhstan.

References

There are no known publications at this time.

Latvia¹

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|--|-----------------------|
| Volunteer hospice team | ○ |
| Hospital palliative care support team | 7 (n/a) |
| Home palliative care support team | ○ |
| Mixed palliative care support team | ○ |
| Palliative care units in tertiary hospitals | ○ |
| Palliative care units in non-tertiary hospitals | 6 (91) |
| Inpatient hospice | ○ |
| Day hospice/day care centre | ○ |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Vilnis Sosars and Liga Keisa (adult palliative care unit, Riga); Anda Jansone (paediatric outpatient team, Riga).
- Survey on Oncology in Latvia 2010. Presentation at the Latvian Oncology Centre, Latvian Oncology Association (2nd December, 2011).
- Data from Reinis Joksts (Ministry of Health), Aiga Rurane (WHO National Agency);
- Presentation from Latvia (Vilnis Sosars). Development Capacity of Palliative Care in the European Region. Catalan Institute of Oncology. WHO Regional Meeting (19 - 20 April, 2010) whocc.info@iconcologia.net.
- 29/01/2009 Act of the Cabinet of Ministers No 48 "About the Control Programme of the Oncological Diseases from 2009 - 2015" (protocol No 3, paragraph 47) published in "Latvijas Vestnesis", 29 (4015), 20/02/2009, valid from 29/01/2009.

Additional comments:

- No volunteer hospice teams exist in Latvia (except for separately trained volunteers). A programme of palliative care volunteers for adults in Latvia was organized approximately nine years ago, led by a volunteer coordinator – a psychologist – and initiated by the Soros Foundation. However, it ceased in 2008 due to a number of different reasons e.g. lack of education, lack of motivation, personal problems, and particularly the economic situation in Latvia.
- Each of the seven hospital palliative care support teams consists of a doctor, nurse, social worker and pastor if needed.
- Home palliative care is provided by healthcare professionals working in the seven hospital palliative care support teams based in Riga, Ventspils, Liepāja, Daugavpils, Mazsalaca, Iecava, and Irlava; there is collaboration with family doctors via the telephone and patients and their relatives may be visited on an outpatient basis in Riga, and in general palliative care units outside Riga (up to approximately 30 km).
- In addition, there are 22 acute bed hospitals, eleven nursing homes (7828 beds total), and five oncology institutions in Latvia where patients often receive palliative care on an emergency basis if they are admitted due to rapidly progressive illness or severe symptoms (data from 2010).
- According to the State Programme in Oncology (chapter on palliative care), the Latvian government intends to develop 25 day care centres in the country by 2015.

Palliative care services for children:

There is one paediatric hospital palliative care support team (outpatient setting - no beds) based in Riga; Anda Jansone is in charge of this team which has a number of full-time workers, including a social worker, a psychologist and a chaplain, that provide palliative care consultations for children and family members at home.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|------|--|
| 1995 | <i>Palliative care begins to develop in Latvia as an educational programme.</i> |
| 1996 | <i>The Palliative Care Association of Latvia (PCAL) is formed.</i> |
| 1997 | <i>The first palliative care unit in the country opens at the Latvian Oncology Centre, with 25 inpatient beds and approximately 700 admissions per year.</i> |
| 2000 | <i>A large pilot study is carried out by the Riga Sickness Fund concerning the use of pain killers in palliative care and the cost-effectiveness of patient admittance at the palliative care unit, oncology hospital, and general hospitals.</i> |
| 2000 | <i>Outpatient consultancy for palliative care patients commences at the Latvian Oncology Centre.</i> |
| 2001 | <i>The WHO document, 'Looking Forward to Cancer Pain Relief for all' (1997) is translated into Latvian.</i> |
| 2004 | <i>Four palliative care units open in different regions of Latvia.</i> |
| 2005 | <i>The 'European Union Recommendations for the Development of Palliative Care System in EU countries' is translated and published into Latvian.</i> |
| 2005 | <i>The Palliative Care Association of Latvia marks the publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organization of palliative care) by translating it into Latvian with the support of the Soros Foundation in Latvia and Riga Town Council (Social Affairs Committee).</i> |
| 2005 | <i>The Alpha & Omega Society is established as a non-governmental organization proposing the legalization of euthanasia or medically-assisted suicide (MAS).</i> |
| 2006 | <i>PCAL is re-registered.</i> |

EAPC Palliative Care Euro-Barometer 2005

In 2009, palliative care was included as a Chapter of the State Oncology Programme (2009-2015) and approved by the Cabinet of Ministers of Latvia. Also in 2009, the Cabinet of Ministers approved palliative care as a medical subspecialty

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- In 2009, palliative care was included as a Chapter (IV) of the State Oncology Programme (2009-2015) and approved by the Cabinet of Ministers of Latvia. The main tasks of the Chapter were to develop a comprehensive and accessible system of palliative care in the country, and to improve the quality of life of both oncological and non-oncological patients (29/01/2009 Act of the Cabinet of Ministers No 48 "About the Control Programme of the Oncological Diseases from 2009 to 2015" (protocol No 3; paragraph 47), published in "Latvijas Vestnesis", 29 (4015), 20/02/2009, valid from 29/01/2009);
- In April 2009, the Cabinet of Ministers (2.80, paragraph 408) approved palliative care as an additional doctor's speciality designed as code PP26; this speciality can be obtained by an internist, general practitioner, oncologist, physical and rehabilitation medicine doctor, geriatrician and paediatrician (paragraph 409). Residential time to obtain PP26 is one year of theory and practice (Approved by 24/03/2009 CM No 268 "Regulations of medical persons and those who study or apply the first or the second level professional higher medical education programmes, competence in medicine and volume of the theoretical and practical knowledge of these persons" (protocol No 21; paragraph 61), published in "Latvijas Vestnesis", 58 (4044), 16/04/2009. Valid 17/04/2009).

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: There are now seven hospital palliative care support teams (code 85) in the country with a total of 114 inpatient beds. A specialized palliative care unit with 25 inpatient beds is located at the Latvian Oncology Centre, Riga. General palliative care units are located at Liepāja and Daugavpils (since March, 2010) and there are other palliative care centres at: Ventspils and Mazsalaca (palliative care plus social care); Līvāni (since 2011 - social care service only); Iecava (palliative care plus social care); and Irlava (palliative care plus social care service) [1]. The number of PC beds can be increased or reduced in the centres dependent upon whether more or less social care or palliative care beds are needed [1].
- Nursing homes: There are eleven nursing homes in Latvia (April, 2010) [2].
- Residential homes for the elderly: There are seven mid-term (care) institutions with a total of 699 beds (April, 2010) [2].
- Other community settings: There are 22 acute-bed hospitals (with emergency coverage) and five oncology institutions in Latvia; there are also 1,315 GPs (April, 2010) [2]. There are outpatient facilities (consultancies) in palliative care at Riga (Latvian Oncology Centre), Ventspils, Liepāja, Daugavpils, Mazsalaca, Iecava and Irlava.

[1. Survey on Oncology in Latvia 2010. Presentation on the 2nd December, 2011. Latvian Oncology Centre, Latvian Oncology Association].

[2. Presentation from Latvia (Vilnis Sosars). Development Capacity of Palliative Care in the European Region. Catalan Institute of Oncology. WHO Regional Meeting (19 - 20 April, 2010) whocc.info@iconcologia.net; Data from the Ministry of Health (Reinis Jokssts) and WHO National Agency (Aiga Rurane)].

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

Following the severe economic recession in Latvia (2008-2010), there has been a slight increase in palliative care service provision for non-cancer patients in primary care (GPs). From July 2011 until January 2012, the European Social Fund (ESF) programme in Latvia included the first professional teaching in palliative care that focused on non-oncological diseases. The teaching material, lectures and practical training in this programme was for 60 GPs, specialists and other persons interested in the development of palliative care throughout the country. Teaching was based mostly at palliative care units and performed by palliative care specialists [1].

[1. Palliative Care Programme of Doctors Professional Education. Printed Teaching Materials. Ministry of Health, ESF, Latvian Physicians Society, National Institute of the Society Health. Sosars V, Jansone A, Keisa - Kirse L, Karklina M, Kokina R, Buklovska L, Albina I. Medicinas Apgads. 2011. 152 pages].

Perceived barriers to the development of hospice and palliative care:

- Insufficient funding of palliative care services. Due to severe recession in the country the development of palliative care was delayed for several years; there have been considerable budget restrictions that have affected palliative care activities since 2009.
- Access to palliative care services.
- Lack of certified teaching programs on palliative care at different levels for doctors, nurses, social workers, psychotherapists, pastors, and volunteers.

Perceived opportunities for the development of hospice and palliative care:

- Recognition and support for palliative care initiatives from the Latvian Physicians Society, Ministry of Health, and National Institute of the Society of Health.
- Financial support from the European Social Fund programmes.
- Collaboration with WHO, EAPC and other international palliative care institutions.

Other issues relevant to the development of hospice and palliative care:

The organization of palliative care education in Latvia at different levels (specialized and general, primary care), and developing teaching curricula for both undergraduate and postgraduate students.

Vitality

THE VITALITY OF PALLIATIVE CARE**National Associations of Palliative Care:**

- The Palliative Care Association of Latvia (Paliatīvās aprūpes asociācija Latvijā or PCAL) was formed in 1996 and is representative of the whole country.
- The Children's Palliative Care Society (Bērnu paliatīvās aprūpes biedrība) was formed in 1997 and is representative of the whole country.

Directory or catalogue of palliative care services:

A directory of palliative care services is included in the State Oncology Programme (2009 - 2015).

Congresses, scientific meetings or scientific journals in palliative care:

- Scientific meetings involving approximately 15-20 members of PCAL are held twice or three times each year.
- Approximately six to ten national and international palliative care congresses (interdisciplinary conferences, international symposia, etc.) are held each year involving up to 600 participants.

Palliative care research capacity:

- The Palliative Care Unit, Latvian Oncology Centre, participates in a number of different international research studies (mostly on pain control);
- Palliative care researchers include: Dr. Ilga Albina (ilga.albina@gmail.com); Dr. Lidija Buklovska (lidija.buklovska@gmail.com); Dr. Līga Keisa (liga.keisha@gmail.com); and Dr. Vilnis Sosars (vsosars@inbox.lv).

Palliative care collaboration:

- Palliative care collaborations include: Latvian Pain Study Society and the WHO office in Latvia. Major activities include: academic initiatives (developing palliative care curricula, chapter on pain in oncology and palliative care, postgraduate course in algology (collaboration over eight years)); and working on developing a strategy in palliative care in Latvia.

The Palliative Care Unit at the Latvian Oncology Centre, Riga East University Clinic, provides palliative care education. A training course in palliative care is now available for every medical resident in Latvia

- Other collaborations include: Open Society Institute (translation of Recommendation Rec (2003) 24 of the Committee of Ministers to Member States on the Organization of Palliative Care/Council of Europe (Recommendations, 2005)) into Latvian in conjunction with the Latvian International Task Force group; EAPC (participation in Editorial work of "Standards and Norms for Hospice and Palliative Care in Europe - the EAPC White Paper", 2009. This document is included in palliative care teaching programs and received the European Association of Palliative Care Special Award for Editorial Work on Standards in Palliative Care, 2009); Lithuanian Pain Society (participation in International Conferences e.g. Pain in Baltics, November 2011 and April, 2012); Mission Opportunities Short-Term. Michigan, Ann Arbor, USA; Manager: Gayle Sommerfeld (participation in international hospice short-term missions - Kenya, India, China, Kyrgyzstan - collaboration since 1999); WHO, Barcelona Oncology Centre (work on developing a strategy in palliative care).
- PCAL was established in 1996, but educational work started in 1994 in close collaboration with the Polish palliative care movement (Professor Jacek Luczak, Poznan); this collaboration continued until 2002 when all the Central and Eastern European countries united to perform educational work and practical training (1994 - 2002). In 1999, the Task Force Group was organized, different recommendations were proposed, specialists were trained and instructors in palliative care for each country were prepared. Teaching sessions in Poznan, and Puszczkowo (Poland) were sponsored by the Open Society Institute until 2002. The impact of this high-level international training resulted in the pioneering of palliative care in Latvia at that time e.g. an established palliative care association and the opening of the first specialized palliative care unit in 1997 at the Latvian Oncology Centre. In 2004, six other units opened in different parts of Latvia and outpatient consultancies were also developed.

Worldwide palliative care alliance level of development:

3A (Isolated palliative care provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006**General developments in palliative care education and training initiatives:**

- The main documents related to palliative care education are within the State Oncology Programme (2009 - 2015): Six accredited programmes are to be developed for physicians (24 Credit Points (800 hrs) plus 500 pages of educational materials); doctor's assistant, social worker, chaplain (14 Credit Points (560 hrs) plus 400 pages of educational materials); nurses (10 Credit Points (400 hrs) plus 30 pages of educational materials); caregivers (150 hrs) plus 150 pages of educational materials. Responsible institutions include: University Medical Faculty, Nursing Schools, Social Educational Establishments, and Pastoral Associations (29/01/2009 Act of the Cabinet of Ministers No 48 "About the Control Programme of the Oncological Diseases from 2009 to 2015" (protocol No 3; paragraph 47), published in "Latvijas Vestnesis", 29 (4015), 20/02/2009, valid from 29/01/2009);
- 152 pages of printed materials were distributed to 60 physicians participating at the European Social Fund (ESF) programme organized by the Ministry of Health, Physicians Society and National Institute of the Society for Health. The ESF programme commenced in July 2011 and ceased in January 2012. 90 credit hours were provided for those who participated in the ESF and palliative care programme. It was subsequently decided to extend the printed material and publish it as an "Introduction to Palliative Care" (approximately 200 - 250 pages); the intended target audience were doctors, nurses, students, social care givers, chaplains and volunteers (Palliative Care Programme of Doctors Professional Education. Printed Teaching Materials. Ministry of Health, ESF, Latvian Physicians Society, National Institute of the Society for Health Medicinas Apgads. Sosars V, Jansone A, Keisa-Kirse L, Karklina M, Kokina R, Buklovska L, Albina I. 2011. 152 pages);

- Several other professional teaching materials have been printed for doctors, residents, students, and social workers on pain management (Pain Management in Palliative Care (Latvian), booklet, Sosars V, Keisa L, Riga, 2008, 82 pages); pain in gerontology and neuropathic pain (Pain Problems in Gerontology and Neuropathic Pain in Palliative Care. Booklet. Sosars V, Albina I. Riga, 2009, 34 pages); the use of Fentanyl in pain management (Fentanyl in Pain Management. Booklet. Sosars V., Riga, 2009, 39 pages); and some other teaching materials about Morphine (Morphine in Clinical Practice. Booklet. Sosars V. Ratiani S, Riga, 2007, 28 pages) and treatment of bone metastases (Therapy Principles of Metastatic Bone Lesions. Booklet. Sosars V, Keisa L, 2007, 23pp).

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Special short-term courses for medical faculty students include theory (1-2 hours) and practice (1 hour) - usually a total of three hours each semester. The main topics are an interdisciplinary approach to palliative care and the basics of pain control.
- Nursing: A short course (5-6 hours) for medical nurses including both palliative care theory and practice has been developed at the palliative care units for each semester.
- Social work: Social workers are educated at different social education establishments and on different levels. They receive special clinical training from social workers experienced in palliative care in a variety of settings. At the Latvian Oncology Centre (443 inpatient beds, including 25 palliative care beds), there is only one social worker dealing with many different social problems. In some regions, there is a link with the social care department so patients or their relatives can receive information and practical support if required.
- Other professions: There are different consultants such as neurologists, traumatologists, surgeons, oncologists, and psychiatrists who are high-level specialists and can solve different problems at palliative care units if needed. There is the Chaplains Association of Latvia which has a graded teaching programme; every palliative care unit has a pastor available if needed to solve existential and spiritual problems. The Latvian Oncology Centre has the first trained psychotherapist in palliative care who participates in the work of the multidisciplinary team - consulting with patients, and teaching students, residents and medical doctors. There is no volunteer movement in Latvia at the present time; there are sporadic cases where students are short-term volunteers and participate in the team's work but there are no formal programs developed to specifically train volunteers.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: Residents from both University Medical faculties are trained in palliative care theory and practice at the Palliative Care Unit, Latvian Oncology Centre. The average time spent there is two weeks, but in it can be extended to up to two months. Each year, the Centre trains approximately 20 - 30 medical residents, future GPs or doctors from other specialities.
- Nursing: The duration of nurse training ranges from several hours up to two or three weeks. Training theory includes the use of different manipulations and dressings.
- Social work: A social worker receives their clinical training under the auspices of another social worker already experienced in palliative care in the field of legislation, work with clinical documentation, and social support. The training programme is highly variable and focuses on future work possibilities in palliative care. High level social worker training takes place at the Latvian Oncology Centre where the social worker participates in the work of the multidisciplinary team, including ward rounds, discussions and training programs for different medical workers.
- Other professions: The same as for undergraduate palliative care education initiatives.

Translation of palliative care documents or other materials:

Translation of a palliative care document from English to Latvian was conducted by the International Task Force group (Open Society Institute) in 2005 (Recommendation Rec (2003) 24 of the Committee of Ministers to Member States on the Organisation of Palliative Care. Council of Europe. Recommendations - book, translated into Latvian. Sosars V (ed.), translation Sosare M., Vevere Z, Sosars P. Nacionālais apgāds. Printed in 2005, 64 pp, Riga).

Initiatives to develop healthcare professional leadership in palliative care:

The Palliative Care Unit at the Riga East University Clinic has developed palliative care initiatives and become the leading teaching, research and practice centre in the country. Since 2006, four multi-centre studies on pain control have been successfully performed at the unit. Students, medical residents, and GPs receive academic education in palliative care at the centre.

Officially recognized medical certification:

- Since April 2009 (after the State Oncology Program was accepted), a sub-specialty in palliative medicine was accredited by the Latvian Physician Society (all specialties and sub-specialties are accredited by this organization); a minimum of one-year postgraduate training (theory and practice) is required to be accredited. Physicians working in the areas of oncology, family medicine, geriatrics, internal medicine, neurology, rehabilitation, and paediatrics are eligible for accreditation (oncologists should have at least ten years practical experience of working with patients in the advanced stage of disease, have performed scientific studies (e.g. on pain control), and have related publications).
- However, the teaching programmes relating to this accreditation are incomplete; they will be finalized at two Medical University Faculties - Latvian University and Riga Stradins University. Although accreditation is not yet officially finalized in Latvia, there are approximately 20 physicians who are well-trained in palliative medicine and are full-time workers at different palliative care organisations - one physician works in specialized palliative care and six in general palliative care; one physician works in a paediatric palliative care outpatient setting.
- Palliative medicine as an additional doctor's speciality is designed by the code PP26 with the residential term of one year. Six accredited programs are included in the State Oncology Programme and physicians receive 24 Credit Points for 800 hours of study and reading 500 pages of educational materials (different practical skills are also obtained during the year of training);
- A training course in palliative care is now available for every medical resident; training lasts from two weeks up to two months and is provided by the Latvian Oncology Centre (Palliative Care Unit) which is a tertiary-level institution.

Capacity of palliative care workforce training in Universities and Medical Schools:

- In Latvia, there are four medical schools: two University Medical Faculties and two Medical Schools for nurses; all four institutions dedicate time to palliative medicine in the curricula as a mandatory component. Palliative care educational curricula began to develop from 2010 once the State Oncology Program (2009 - 2015) commenced in practice.
- There are an estimated eight "other category" Professors of Palliative Medicine - two "assistant principal doctors" and six doctors teaching palliative care for family doctors and other interested persons (no Chair in Palliative Medicine currently exists in Latvia). All palliative care teaching is regulated by PCAL, a Chair in Oncology and the two university medical faculties. All teachers in palliative care are highly qualified in either oncology or paediatrics and work full-time in different palliative care settings.
- There are approximately ten "other professors (non-medical)" working as "assistant principals", teaching social, psychological and pastoral work. The number of actual education providers is variable as the teams often change in number.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- Basic medications are available in Latvia.
- Discussions and analysis of the situation relating to the availability of essential medications in Latvia has taken place at regional WHO conferences involving representatives of the Ministry of Health, WHO Regional Agencies and palliative care specialists (e.g. Riga, Latvia - January and October, 2008; Holland - March, 2010; Barcelona - April, 2011).

Developments/opportunities/barriers relating to the accessibility of essential medications:

- If a patient is registered with a GP or is admitted to hospital, they have direct access to medicines. If a patient is not registered with a GP, several forms of opioids will not be available to them. Transdermal forms of opioids are not always accessible at the palliative care units due to financial restrictions.
- Participation in the Access to Opioid Medications in Europe (ATOME) project has provided Latvia with the possibility of resolving some of these barriers.

Developments/opportunities/barriers relating to the affordability of essential medications:

- Essential medications are affordable in Latvia; however, the maximum amount (under the inner hospital regulations, 2011) that was allowed to be spent on opioids per patient at the Palliative Care Unit, Latvian Oncology Centre in 2011 was 2 lats (LVL) or 2.85 Euros per day (this figure varies slightly between units);
- Local seminars and round-table discussions are held at the Ministry of Health each year and an annual presentation is conducted at the Parliament sub-commission meeting where specific questions relating to palliative care are also discussed.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

- Recognition of palliative care as a State Programme and legislation designed on a "step by step" basis has improved the stocking, prescribing and dispensing of opioids in Latvia.
- All regulations and legislation relating to the use of opioids in clinical medicine are summarized in the Country Checklist of Latvia presented at the ATOME meeting in Bucharest (17th – 19th November, 2011).

Initiatives to promote attitudinal change in relation to 'opiophobia':

- Printed teaching materials relating to 'opiophobia' have been provided for GPs (because they prescribe opioids at the primary care level);
- There have been regular seminars on this topic for students, medical residents and other interested parties;
- The issue of 'opiophobia' has been discussed at palliative care association meetings, and at Algology and Oncology association meetings also;
- One or two lectures specifically related to 'opiophobia' have taken place at interdisciplinary meetings organized annually by the Latvian Physicians Society in different regions of Latvia (attended by approximately 600 - 800 participants);
- The issue has been addressed in various journal articles, and interviews in the mass media.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is a special review on access to opioid medication for economically disadvantaged persons; although the rules concerning this issue are the same for most groups of patients, in the case of non-oncological diseases, opioids are not reimbursed. However, the Latvian Oncology Centre organized a consortium of specialists and wrote a letter of reference to the financial establishments responsible for this issue to ensure reimbursement for opioids in all cases. In general, following an evaluation of the patient's condition, all groups of patients can obtain support from these institutions for one year and longer if needed. In future, changes should be made to legislation so as not to discriminate against any group of patients requiring palliative care and opioids for medical use. This is a future task for palliative care activists in Latvia.

Initiatives that consider access to essential medication as a legal and human right:

The initiatives mentioned above consider access to essential medication as a legal and human right.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006**Most important legal or policy changes affecting the development of hospice and palliative care:**

Including palliative care in the State Oncology Programme (2009-2015) and the recognition of palliative care as an additional specialty.

The impact of these policy changes and ways in which they have been important:

In the frame of the State Oncology Programme (2009-2015), palliative care as a graded and comprehensive system should be developed; a variety of resources should be accessed to provide palliative care for both oncological and non-oncological patients (29/01/2009 Act of the Cabinet of Ministers No 48 "About the Control Programme of the Oncological Diseases from 2009 to 2015" (protocol No 3; paragraph 47), published in "Latvijas Vestnesis", 29 (4015), 20/02/2009, valid from 29/01/2009).

Development of a national palliative care consensus:

Good cooperation in the field of palliative care education commenced between the Medical Faculties of the Latvian University and Riga Stradins University. Regular teaching of medical residents and students started in 2006 at the specialized Palliative Care Unit, Latvian Oncology Centre. More extended teaching material on pain control was published in 2008 for GPs (82 pages). In September 2008 an Essential Medicines List for palliative care was produced. Latvia will continue to participate in the ATOME project until 2014.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

Each year, there are at least two or three significant meetings with stakeholders and policy makers to develop palliative care strategies.

Development of an advocacy framework for integrating palliative care into the health care system:

An advocacy framework for integrating palliative care into the health care system has been developed with the support of the Ministry of Health and the Latvian Physicians Society.

Strategies to improve political awareness and government recognition of palliative care:

- A situation analysis of palliative care in Latvia.
- Round-table discussions with policy makers and other key stakeholders (e.g. regarding limited access to services).
- Seminars on specific problems related to palliative care (e.g. opioid usage and availability, etc.)
- Public debate, journal articles, media initiatives, etc.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

- There is only a small amount of funding provided by the Latvian government (mainly for repair of the palliative care units, but not to improve services);
- There are some small private donations for necessary equipment (e.g. to buy new beds for the palliative care units);
- Some NGOs provide funding to purchase medical items (for example, Mission Pakapieni);
- The Catholic and Lutheran churches arrange chapels at the palliative care units.

There has been support for palliative care from the Latvian Physicians Society, Ministry of Health, and National Institute of the Society of Health; financial support from the European Social Fund; and collaboration with international palliative care organizations

Involvement with the European Union in relation to hospice and palliative care initiatives:

The ESF teaching programme as mentioned previously.

Development of initiatives framing palliative care as a 'human right':

There are barriers to the concept of palliative care as a 'human right' in Latvia; access to palliative care services is restricted due to a limit on patient numbers each month; palliative care is not yet focused on non-oncological diseases; there are limits on opioid prescribing, with no possibilities of "emergency" prescription (e.g. if a patient ran out of morphine at weekend); there are very limited resources for palliative care units and very low salaries for those who work in palliative care settings.

General legislation relating to palliative care:

The inclusion of palliative care in the State Oncology Programme (2009-2015).

Published national documents relating to palliative care standards and norms:

Palliative Care Programme of Doctors Professional Education (printed teaching materials); Ministry of Health; ESF; Latvian Physicians Society; National Institute of the Society Health. Medicinas Apgads. Sosars V, Jansone A, Keisa-Kirse L, Karklina M, Kokina R, Buklovska L, Albina I. 2011. 152 pages. 2011 first edition.

National Plan or Strategy of Palliative Care:

The State Oncology Programme (2009-2015) describes the structural and educational development of palliative care in Latvia.

National Cancer Control Strategy:

There is a National Cancer Control Strategy in Latvia.

National HIV/AIDS Strategy:

There is no National HIV/AIDS Strategy in Latvia.

National Primary Health Care Strategy:

The document "Introduction of Outpatient and Inpatient Care from 2005 - 2010" approved by the Cabinet of Ministers, 28th December, 2005, Nr. 854 stating the position of palliative care according to levels of service.

Designated policy maker for the delivery of palliative care services:

A designated policy maker for the delivery of palliative care services is included in the State Oncology Programme (2009-2015); the responsible organizations are the Ministry of Health, State Insurance Companies, and professional associations (although all palliative care activities are limited due to severe State budget restrictions).

Department of Health specific responsibility for the delivery of palliative care services:

- The specific responsibilities of the Department of Health (Ministry of Health) are as follows: define the necessity for palliative care; determine the finances for palliative care; make changes to medical and social legislation where necessary; organize palliative care structures; promote an interdisciplinary approach in palliative care education;
- Specific tasks are designated in the State Oncology Programme (2009-2015); for example, in local palliative care units, specific responsibility for the social care aspect of the financial budget belongs with the local government.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

The quality of palliative care provided is sometimes audited by the State Control Commission.

Opioid legislation/Pain guidelines:

- Opioid: There is only one prescription form for GPs and hospital doctors; strong opioids are available at the pharmacies and the hospital units.
- Pain guidelines are available: Recommendations on Prescribing Reimbursed Pain Killers (Riga, 2004). Every six months, the list of reimbursed pain killers is revised and published in a booklet disseminated by the Ministry of Health to all health care professionals.
- In 2012, the PCAL plan to prepare national guidelines in pain control and palliative sedation.

Funding of palliative care services:

- Payment for palliative care consultation depends on the level of provision required and the particular specialist. In general, no additional payment is required from the patient unless the consultation is with the head of the unit at the specialized level (approximately 28-30 Euros).
- Full payment may be required for palliative care hospitalisation if it is an unplanned admission (approximately 28-35 Euros per day); partial payment may be required for palliative care hospitalisation if it is a planned admission (approximately 7-15 Euros per day). No payment is required for hospitalisation if a person belongs to the "specialized category" (e.g. has a low income, or is a disabled person recognized by the medical commission, or hospital medical staff).
- Full payment for palliative care medications is required from patients with non-oncological disease in the outpatient setting; partial payment for palliative care medications may be required at the primary care level depending on the cost of the medication (25-50% of the value of the medication);
- At the primary care level the majority of medications needed for palliative care are reimbursed.
- The majority of reimbursed medications are only for oncological palliative care patients. Patients with non-oncological diseases should expect to pay 100% of the cost of prescribed medications. Exceptions are cases with high annual costs of medication where palliative care specialists write and sign a special reference for the Ministry of Health in relation to the individual patient stating the need for constant (and necessary) treatment.

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

This is a slow process in Latvia as hospice and palliative care (by narrow definition) becomes increasingly associated with death and dying. In a broader sense, palliative care is gradually becoming more clearly associated with the diagnosis of "incurable" disease throughout its trajectory until death. There is now increased public understanding about oncological and non-oncological diseases, pain and other symptom control.

Major public discussion, debate or controversy about hospice and palliative care:

There are public debates, interviews about palliative care and newspaper articles on the subject at least every three months (and often more regularly). Occasionally, there are radio or TV debates about euthanasia.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

Many newspaper and journal reporters are quite interested in the problems relating to palliative care (and also future possibilities).

Hospice or palliative care 'success' stories:

In June 2010, the administration office of the Latvian Oncology Centre wanted to transfer the palliative care unit to a general hospital that was located further away and was not linked with oncology (the wards were not suitable to provide palliative care services). The existing palliative care unit was intended to be used for either plastic surgery or stem cell transplantation, despite the fact that plastic surgery is more orientated to private practice and stem cell transplantation is very limited by its expensiveness and poor financial reimbursement from the State health sector. Palliative care only survived at the Latvian Oncology Centre due to TV, newspaper reports and very active societal support (thereby increasing its popularity).

Initiatives seeking the legalisation of euthanasia or assisted dying:

These are some small articles mostly reflecting on initiatives in Holland, Belgium or Sweden. As the health care system needs to be reformed and financed, there are no significant attempts to legalize euthanasia or medically-assisted suicide. Without a sufficient budget in medicine or palliative care, access to services is limited and not readily available; therefore, euthanasia or medically-assisted suicide would be, in essence, a simple solution to solve medical and care problems. It will especially target the most vulnerable groups in society such as pensioners, fatally ill people with severe symptoms such as pain, dyspnoea, advanced oncology disease, HIV/AIDS, resistant TB (which is a problem in Latvia), people with cirrhosis, hepatitis C, and other illnesses where treatment is partially reimbursed and rather expensive. All the major churches in Latvian society (Lutheran, Orthodox, Catholic and Baptist) are opposed to euthanasia or assisted dying.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

There are several tasks in a five-year trajectory of palliative care development: increase funding; organize effective palliative care structures throughout Latvia; promote patient access to palliative care services; develop education curricula; continue work on palliative care guidelines; improve legislation on opioid availability; promote palliative care in non-oncological diseases; provide the Latvian Oncology Centre with the status of Centre of Excellence or collaborating WHO Centre (in order to continue its work and avoid future bureaucratic manipulations and endless "reforms"); promote private initiatives and investments in palliative care; enhance international cooperation e.g. with WHO, Open Society Institute and palliative care organizations such as EAPC.

Most significant issues facing hospice and palliative care in the next three years:

- Finances.
- Education.
- Human resources.
- Legislation.
- PCAL was established at 1996 and from that time has played a leading role in organization of the palliative care system in the country. As an NGO it is free to negotiate both with the State health organizations and other NGOs.

Implications for palliative care relating to the current economic crisis:

Palliative care needs to be recognized as one of the priorities in the Latvian health care sector. The State health budget should be gradually increased according to the growing need for palliative care in the country. Palliative care is the most economically viable way to assist people with both oncological and non-oncological diseases.

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Lithuania¹

NATIONAL ASSOCIATION

Palliative Medicine Association of Lithuania

*Lietuvos paliatyviosios
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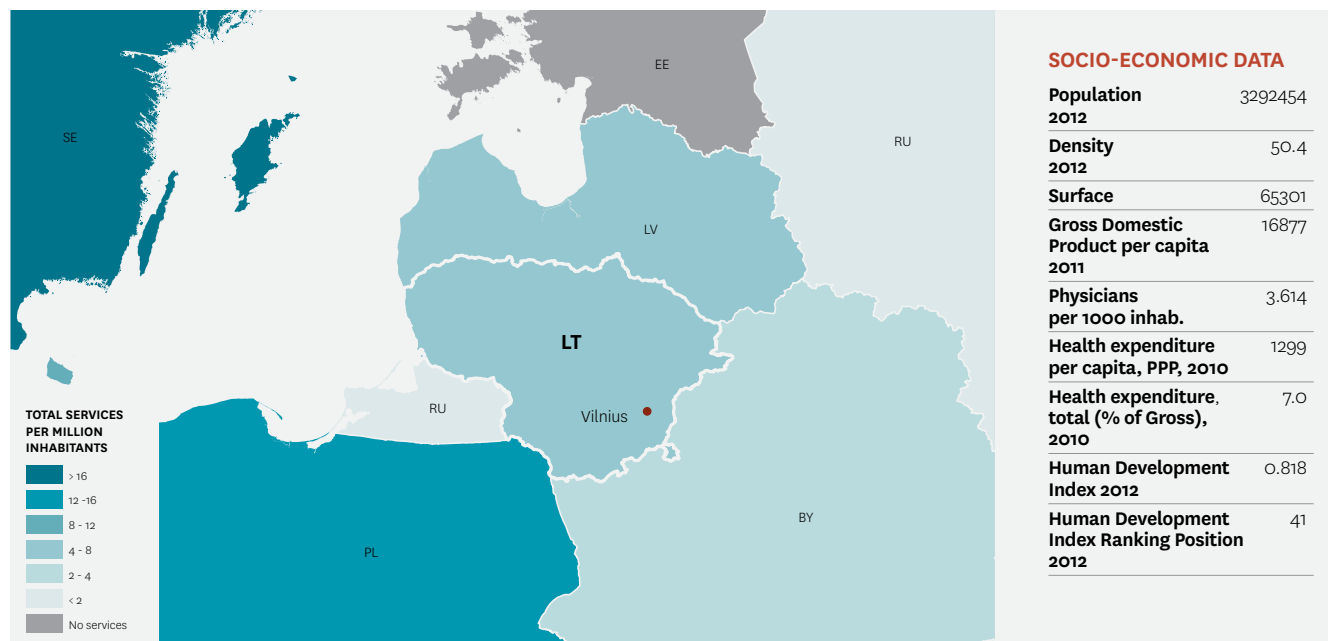
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Additional information provided by:
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 0 |
| Home palliative care support team | 14 |
| Mixed palliative care support team | 1 |
| Palliative care units in tertiary hospitals | 1 (10) |
| Palliative care units in non-tertiary hospitals | 8 (86) |
| Inpatient hospice | 0 |
| Day hospice/day care centre | 1 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

Odeta Vitk nien; Irena Danelien; Asta Šileikien; Adolfas Augustinavius; Raimonda Ulianskien; Viktorija Žvaliauskien; Žaneta Valiulien; j. Buterleviciute; Dalia Skorupskien.

Additional comments:

- Since 1995, the Palliative Care and Pain Control Unit in Vilnius Oncology Institute has provided palliative care services to patients in the hospital, outpatient clinic and at home. Its palliative care team consists of two physicians, two nurses and one social worker.
- The Center of Integrated Services in Panevėžys provides palliative care at home.
- St. Francis Cancer Support Center and the Palliative Medicine Centre in Kaunas have begun to prepare volunteer palliative care services. There are individual volunteers in health care institutions but they do not provide bereavement support.
- There is a Unit of Palliative Oncology in Kaunas Clinic of Lithuanian Health Sciences University Hospital. The head of this Unit is Dalia Skorupskien.
- In 2010, there were 37 healthcare facilities which obtained licences for providing palliative care services at home; 13 of them provided full home palliative care services (physicians, nurses, and social workers).
- In 2010, there were 57 health care facilities which obtained licences for providing palliative care services in hospitals (most of them were Nursing Hospitals). The number of beds for palliative care patients is not fixed in the healthcare network – it depends on the total amount of money determined by the Patient Fund each year. 32 Hospitals received a small sum of money and could provide only 0.2-2.7 palliative care beds per year and therefore could not provide palliative care services. Full palliative care services were provided in eight hospitals (physicians, nurses, social workers, priests, etc.)
- In 2010, there were 13 healthcare facilities which obtained licences for providing palliative care services at day care centres (but palliative care services were provided in just one).

Palliative care services for children:

There are three paediatric home palliative care support teams, and two paediatric palliative care units in non-tertiary hospitals.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

- | | |
|-------------|---|
| 1995 | The Palliative Medicine Association of Lithuania is established; the Association of Pain is established; the law of prescription and control of opioids is ratified; the WHO document "Symptom Relief in Terminal Illness" is translated into Lithuanian. |
| 2003 | The Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organisation of palliative care) is translated and published in Lithuanian. |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- In 2007, the Ministry of Health issued the Order on the Inventory for Requirements of Palliative Care Services for Adults and Children. Palliative care was legitimated as a separate field of medicine.
- In 2008, the Ministry of Health issued an Order on the Base Price Approval for Palliative Care Services for Adults and Children.
- The establishment of hospices has commenced.

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: Palliative care is provided in oncology hospitals, at the nursing departments of city and district hospitals, and in palliative care and nursing hospitals.
- Nursing homes: Palliative care is not provided in nursing homes (it is provided in nursing hospitals).
- Residential homes for the elderly: There is no information available at this time.
- Other community settings: Palliative care is also provided on an outpatient basis and at home by health centers (family clinics) and private family clinics. Assistance is also provided in consulting rooms.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

According to the Order of the Minister of Health (2007), palliative care must be provided to non-cancer patients as well as patients with cancer.

Perceived barriers to the development of hospice and palliative care:

- Low (insufficient) tariffs for palliative care services and too low a level of government financing;
- It is difficult to ensure effective multidisciplinary team-based provision of palliative care services because the National Health Insurance Fund only allocates 4-6 palliative care beds to each licensed healthcare institution (hospital).
- Palliative care is not a priority field of medicine in the healthcare system.
- Politicians are not interested in palliative care.
- There is no continuity of training for healthcare professionals following an obligatory course of 36 hours in palliative care.

In 2007, the Ministry of Health issued the Order on the Inventory for Requirements of Palliative Care Services for Adults and Children; palliative care was legitimated as a separate field of medicine

Perceived opportunities for the development of hospice and palliative care:

- The Ministry of Health should amend the laws passed in 2007 and 2008 in order to increase palliative care tariffs and increase the number of beds for healthcare institutions licensed to provide palliative care services. This would help to ensure more effective multidisciplinary teamwork.
- The Ministry of Health need to prepare and validate palliative care standards.
- Independent palliative care institutions (hospices) and palliative care day centers need to be established.

Other issues relevant to the development of hospice and palliative care:

- Knowledge about palliative care in Lithuanian society is insufficient; the mass media does not provide enough information about palliative care (it is mostly provided during World Hospice and Palliative Care Day).
- Palliative care is not included in the undergraduate studies of future physicians.
- The establishment of volunteer organizations is still in its initial stages – there is a lack of experience and tradition.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

The Lithuanian Palliative Medicine Association (Lietuvos Paliatyvosios Medicinos Draugija) (LPMA) was established in 1995; it has a website (www.paliatyvagalba.lt) and is representative of the whole country.

Directory or catalogue of palliative care services:

There is no information available at this time.

Congresses, scientific meetings or scientific journals in palliative care:

- There is a National Palliative Care Conference held annually that is dedicated to World Hospice and Palliative Care Day and attended by 200-300 participants.
- Meetings of the LPMA are held every two months, attended by approximately 20-30 members.

Palliative care research capacity:

Researchers include: Professor Arvydas Šeškevičius (Kaunas Lithuanian Health Sciences University - Cachexia (2008) Master theses scientific research); Rita Kašinskienė ("Management of Palliative Care services at Nursing Hospitals"); Laimutė Rožukienė ("Knowledge and attitude towards euthanasia of nurses working at hospitals"); Evelina Bataitienė ("Management of psychosocial services for the relatives of palliative care patients at Nursing Hospital"); Violeta Iliukevič ("Assessment of palliative care needs of family members"); Žaneta Valiulienė ("Care problems of oncology and heart chronic failure patients and their relation with spirituality"); Žydrūnė Luneckaitė ("Quality of life oncology patients relation with social psychology factors and palliative care"); Danutė Butėnienė (Vilnius University Medical Faculty Master theses scientific research - "Quality of life and internal harmony in Palliative Care"); Jacek Luczak, Aldona Gaizauskiene, Vida Miknėviciene (Panevėžys) "Palliative Care in Lithuania" (Raimonda Ulianskiene Regional Palliative Care Program).

Palliative care collaboration:

- LPMA have collaborated with British Fund "The Tiltas Trust" to finance booklet publishing and travelling fellowships for four LPMA members to Northern Ireland;
- Kaunas Nursing Hospital collaborates with St. Christopher's Hospice in London and St. Luke's Hospice in London. Twinning began with St. Luke's in 2006; Chief Executive Mike Coward has participated in Lithuanian conferences, and physician Charles Daniels has delivered lectures for members of the LPMA. Members of Kaunas Nursing Hospital staff have twice attended St. Luke's for palliative care training and attended St. Christopher's in September 2011. Kaunas Nursing Hospital also collaborates with Hospice "Światło" in Toruń (Poland) and Hospice Sw. Łazarza in Kraków.
- St. Francis Cancer Support Center (Kretinga) collaborates with "Mustard Tree Cancer Support Center" (Plymouth); Garliava Family Clinic and Family Health Solutions collaborate with Hasselberg Hospital (Germany).

- LPMA and the Palliative Care and Pain Control Unit in Vilnius Oncology Institute collaborate with Poznan University of Medical Sciences, Department of Palliative Medicine and Hospice "Pallium" (Poland).
- NGO "Home Care and Apostolate Department" in Lithuanian Caritas collaborate with Caritas Europe.
- LPMA members have participated in conferences, seminars, and internships in Poland.
- Pioneers include: Kaunas Nursing Hospital (1993); Palliative Care and Pain Control Unit in Vilnius Oncology Institute (1995); LPMA (1995); The Center of Integrated Services in Panevėžys (2003); St. Francis Cancer Support Center in Kretinga (2009); Palliative Medicine Center in Kaunas (2009).
- Kaunas Nursing Hospital was established in 1993 through the initiative of charitable organisation "Caritas" to provide palliative care services to the terminally-ill. The hospital became an honorary member of the Information Service of St. Christopher's Hospital in London (1993). Cicely Saunders visited the hospital in 1996. Members of hospital staff participated in the 13th World Palliative Care Congress in Montreal, and in the 11th EAPC Congress in Vienna (four posters), and have presented seminars in Salzburg, London, Budapest, Brussels, Poland, Latvia, and Praha.
- Palliative Care education for nursing and medicine students is provided at Kaunas Lithuanian Health Sciences University (Professor Arvydas Šeškevičius).
- Since the announcement of World Hospice and Palliative Care Day (2004), LPMA has organized many events: an annual National Palliative Care Conference; a concert in one of the main Churches in Kaunas; a basketball game between students of the Medical Academy and the Priests Seminary; participations in radio broadcasts; and numerous articles in the media. Speakers from abroad (from some of the above mentioned institutions) have participated in these events.

Worldwide palliative care alliance level of development:

4A (Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

Palliative care is taught as a subject at some universities and colleges (at some institutions, teaching of palliative care is combined with geriatrics).

Specific developments in under-graduate palliative care education initiatives:

- Medicine: There is no teaching of palliative care.
- Nursing: Palliative nursing is taught as a subject at universities and colleges. At some colleges, teaching of palliative care is combined with geriatrics.
- Social work: Students are taught palliative care during their studies at the Lithuanian University of Health Sciences (but it is not taught as a separate subject).
- Other professions: Palliative care is not taught as a separate subject to other healthcare professionals.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: At the Lithuanian University of Health Sciences, palliative care is taught as a separate subject to all resident family physicians (36 hours).
- Nursing: The Lithuanian University of Health Sciences provides multidisciplinary teamwork-based professional qualification courses in palliative care for nurses (36 hours). Some colleges offer professional qualification training in palliative nursing.
- Social work: The Lithuanian University of Health Sciences provides multidisciplinary teamwork-based professional qualification courses in palliative care for social workers (36 hours).
- Other professions: The Lithuanian University of Health Sciences provides multidisciplinary teamwork-based professional qualification courses in palliative care for psychologists and other medical specialists (36 hours).

Translation of palliative care documents or other materials:

- In 2008, Kaunas University of Medicine published a textbook "Palliative Nursing" (by A. Šeškevičius) for students and practitioners.
- In 2010, a book on the history of the activity of the LPMA - "A Granted Hope" (by A. Šeškevičius) - was published.
- In 2011, the booklet "A Practical Guide to the Spiritual Care of the Dying Person" was translated from English into Lithuanian.
- In 2012 the booklet "Standards and norms for hospice and palliative care in Europe - The EAPC White paper" (by A. Šeškevičius) - was published.

Initiatives to develop healthcare professional leadership in palliative care:

There is no information available at this time.

Officially recognized medical certification:

Palliative care services are provided by healthcare professionals who have completed not less than 36 hours study in an accredited education institution (certified). This form of accreditation commenced in 2007, and since that time approximately 600 healthcare professionals have been accredited in this way.

Capacity of palliative care workforce training in Universities and Medical Schools:

- Lithuania has nine medical schools (three universities and six colleges). Two of them have palliative medicine as a mandatory component: Kaunas Lithuanian Health Sciences University (family physicians residency and palliative care in the nursing curriculum); and Klaipėda University (gerontology and palliative care for nurses - 4 credits).
- Palliative medicine is available as an optional component in two colleges: Klaipėda State College (palliative care for nurses); and Utena College (palliative care for nurses).
- There is one full Professor of Palliative Medicine (personal experience - in Kaunas Lithuanian Health Sciences University).
- There are two Assistant Professors (one in Kaunas Lithuanian Health Sciences University/one in Klaipėda University).
- There are five lecturers in palliative care in Lithuania.
- There are two "other professors" (personal experience - in Kaunas Lithuanian Health Sciences University).
- There is also one full professor (non-medical) and one assistant professor (non-medical).

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- Availability of the majority of essential medications is sufficient, and the range of essential medications has been expanded.
- Oral morphine is produced in Lithuania.
- The main essential medications are available without restriction.

Developments/opportunities/barriers relating to the accessibility of essential medications:

Most essential medications are accessible to patients.

Developments/opportunities/barriers relating to the affordability of essential medications:

- Medications for oncological and onco-haematological patients are reimbursed 100% by the Compulsory Health Insurance Fund. For patients with confirmed work disability and retired individuals with a high level of special needs, tramadol is reimbursed 100%.
- Most medications are reimbursed according to the list confirmed by the Ministry of Health (Order of the Minister of Health of the Republic of Lithuania, May 16 2008, No. V-469).
- Medications for non-cancer patients may not be reimbursed.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

- In 2007, the Minister of Health of the Republic of Lithuania issued an Order concerning the issuing of licenses for the importation of narcotic and/or psychotropic substances for personal treatment needs.
- Access to reimbursed medications (both narcotic and other) is regulated by legal acts (1997, 2000, 2002, and 2004).

Initiatives to promote attitudinal change in relation to 'opiophobia':

The Lithuanian Pain Society has organized training courses for family physicians concerning the prescription of opioids. During conferences, the Lithuanian Pain Society has provided lectures about the benefit of opioids to all physicians and nurses. The Society also organizes a yearly "Pain Week" where they explain the usefulness of opioids in analgesia to the general public.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

The IAHP-C-WPCA Joint Declaration and Statement of Commitment to Pain Treatment as a Human Right was translated into Lithuanian by LPMA; the Lithuanian version was signed by the President and the Chair of LPMA as well as by the Minister of Health.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006**Most important legal or policy changes affecting the development of hospice and palliative care:**

- In 2007 and 2008, palliative care was legitimated as a separate field of personal healthcare.
- Order in the Inventory for Requirements of Palliative care Services for Adults and Children (2007).
- Order on the Base Tariff Approval for Palliative Care Services for Adults and Children (2008).

The impact of these policy changes and ways in which they have been important:

- Once palliative care had been legitimated, the establishment s commenced.
- The State Health Care Accreditation Agency under the Ministry of Health issues licenses for the provision of palliative care services.
- The Lithuanian University of Health Sciences has introduced postgraduate professional qualification studies in palliative care.

Development of a national palliative care consensus:

By the Order of the Minister of Health, palliative care was legitimated at the national level. In 2011, the Lithuanian Pain Society issued recommendations for diagnostics and treatment of "Cancer Pain".

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

During 2006-2008, members of LPMA formed an initiative group to develop the legal basis for palliative care. Participants of the national LPMA conferences include a representative of the Ministry of Health responsible for palliative care, and a member of the Committee on Health Affairs at the Seimas (Parliament) of the Republic of Lithuania.

Development of an advocacy framework for integrating palliative care into the health care system:

The National Health Committee included palliative care in its "Cancer Prevention and Control" and "Prevention of HIV/AIDS and Drug Addiction" implementation programs.

Strategies to improve political awareness and government recognition of palliative care:

The importance of palliative care is discussed on the radio and TV, in articles, booklets, and textbooks. The Ministry of Health organizes meetings with LPMA members and foreign guests. Representatives of the Ministry of Health travelled to Ireland to become familiarized with the palliative care system in that country. LPMA informs members of the Committee on Health Affairs at the Seimas (Parliament) of the Republic of Lithuania and the Ministry of Health about its events (e.g. conferences or commemorations of World Hospice and Palliative Care Day).

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

Since 2008, the Government has allocated separate financing for palliative care.

Involvement with the European Union in relation to hospice and palliative care initiatives:

There is no information available at this time.

Development of initiatives framing palliative care as a 'human right':

The IAHP-C-WPCA Joint Declaration and Statement of Commitment to Palliative Care as a Human Right was translated into Lithuanian by LPMA; the Lithuanian version was signed by the President and the Chair of LPMA as well as by the Minister of Health.

General legislation relating to palliative care:

- Palliative Care was legalized in 2007 by the Health Minister of Lithuania.
- Confirmation of Requirements for Rendering of Palliative Care for Adults and Children. Minister of Health, Order no. V-14, 11January, 2007.
- Replacement of confirmation of requirements for rendering of palliative care for adults and children was confirmed on 16th May 2008 by Health Minister (Order no. V469);
- Approval of palliative care basic tariff for adults and children for palliative care services (inpatient, outpatient, day care, home care, mobile team) was set on 16th May 2008 by the Health Minister Order no. V470;
- Replacement of confirmation of requirements for rendering of palliative care for adults and children was confirmed on 28th August 2009 by Health Minister Order no. V702;
- Replacement of palliative care basic tariff for adults and children for palliative care services (inpatient, outpatient, day care, home care, mobile team) was set on 30th December 2009 by the Health Minister Order no. V1101.
- In 2010, the Minister of Health of the Republic of Lithuania approved the document "Development of Outpatient, Palliative Care, and Nursing Services, and Optimization of Inpatient Services".

Published national documents relating to palliative care standards and norms:

There is no information available at this time.

National Plan or Strategy of Palliative Care:

There is a National Plan of Palliative Care in progress; the program of health care system reform continuation and optimization of infrastructure (Minister of Health, Ord. No. V-160, 29th February, 2008. Replacement of program. Minister of Health, Ord. No. V-912, 24th September, 2008). The tasks in these orders are to improve the infrastructure of healthcare services and establish palliative care services in healthcare institutions (180 inpatient beds for palliative care patients).

National Cancer Control Strategy:

The first strategic document regulating palliative care in Lithuania was the Program of Cancer Prevention and Control (2003-2010) (approved by the Government 10th December, 2003, No. 1593). The document states that palliative care can be offered in Oncology Institutions and Nursing Hospitals.

National HIV/AIDS Strategy:

The National HIV/AIDS and STI Prevention and Control Program (2010-2012) (approved by the Government 7th July, 2010 No.1012) does not contain an explicit reference to the provision of palliative care.

National Primary Health Care Strategy:

The Concept of Primary Health Care Development (Minister of Health Ord. No. V-717, 5th September, 2007) states that palliative care services should be available free of charge.

Designated policy maker for the delivery of palliative care services:

There is one person responsible for the delivery of palliative care services in the Ministry of Health.

Department of Health specific responsibility for the delivery of palliative care services:

As above.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- Order of prescription, medicines and medical devices delivery (sale) for residents (Minister of Health Ord. No. V-112, 8th March, 2002. Replacements in 2004, 2007).
- Pain guidelines have been published by the Lithuanian Pain Society: Neuropathic Pain (2009); Back pain (2009); Cancer induced pain. Recommendations for treatment and diagnostics (2011) (www.skausmomedicina.lt).

Funding of palliative care services:

- There is no payment required for palliative care consultation or hospitalisation.
- Partial payment may be required for palliative care medications; for non-cancer patients, medications may only be 80 per cent reimbursed.
- According to "The program of health care system reform continuation and optimization of infrastructure" (Minister of Health, Order no. V-160, 29th February, 2008), there is specific united development funds for palliative care services in Lithuania - from Ministry of Health and European Union Structural Funds (Allocated to 65,152mln Lt, 55,38mln Lt).

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006**Change in public awareness or perception of hospice and palliative care:**

There has only been limited change in Lithuanian society's awareness or perception of palliative care.

Major public discussion, debate or controversy about hospice and palliative care:

Discussions about hospice and palliative care are broadcast on TV and radio.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

Popular newspapers and TV, promote the philosophy, the aim, the objectives, and the organization of palliative care, and provide information about institutions where palliative care is provided.

Hospice or palliative care 'success' stories:

On the occasion of World Hospice and Palliative Care Day, State Radio and the Catholic Mariah Radio present the concept of palliative care. The listeners are free to ask questions that they find relevant. Also, events on that occasion are organized at churches and theatres throughout Lithuania.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There have been discussions about the legalization of euthanasia in the press, on TV, and at conferences. The Government and the Church have both spoken against the concept. Currently, euthanasia is illegal in Lithuania (Criminal code// State News. 2000 No. 89-2741. The Constitution of the Republic of Lithuania// State News. 1992, No. 33-1014).

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT**The future of hospice and palliative care development:**

Inpatient, outpatient, and daycare palliative care services should be established at separate institutions to ensure the provision of palliative care services on a multidisciplinary team basis.

Most significant issues facing hospice and palliative care in the next three years:

- Most importantly, the Ministry of Health should increase the tariffs for palliative care and should prepare standards to ensure multidisciplinary team-based provision of services to patients.
- Members of LPMA should continue to participate in the initiative group organized by the Ministry of Health for reviewing legal documents.

Implications for palliative care relating to the current economic crisis:

In Lithuania, the economic crisis does not seem to have exacerbated the provision of palliative care, and favourable decisions are expected from the Lithuanian Government concerning the development, reorganization, and financings.

References

Seskevicius A. 2002. "Lithuania: status of cancer pain and palliative care". *J Pain Symptom Manage* ; 24(2):205-7."

Luxembourg¹

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in palliative care

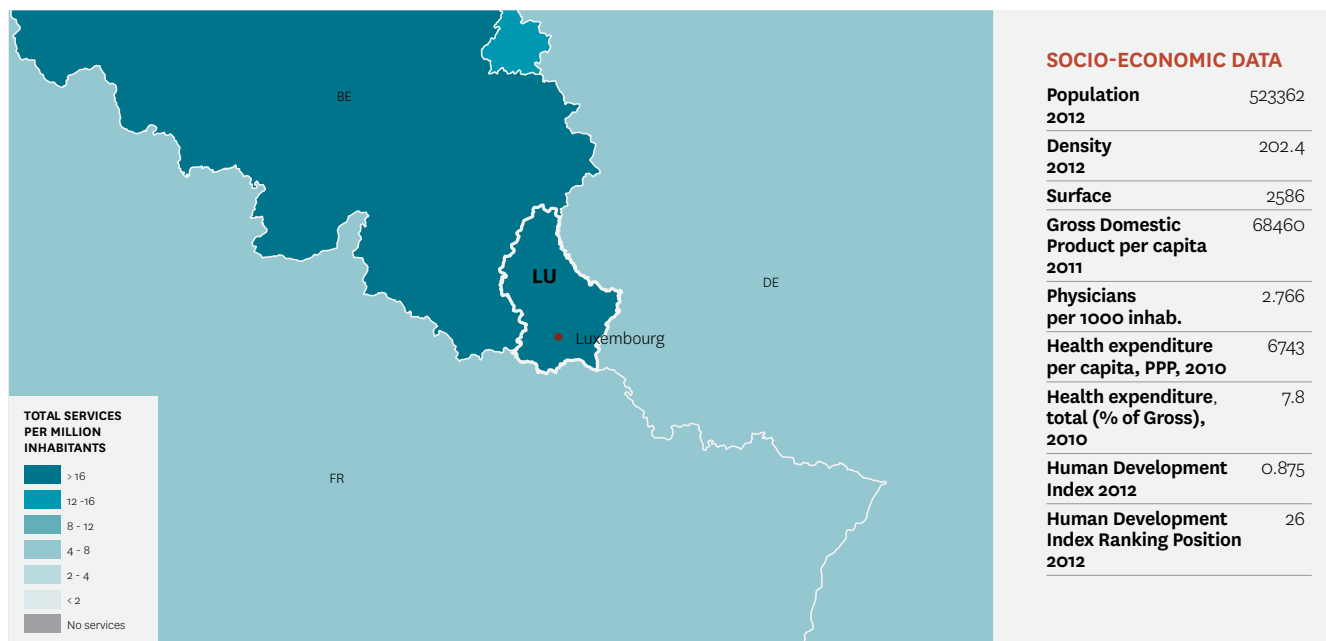
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 2 |
| Home palliative care support team | 2 |
| Mixed palliative care support team | 2 |
| Palliative care units in tertiary hospitals | 3 (19) |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 1 (15) |
| Day hospice/day care centre | 0 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- OMEGA 90: Marie-France Liefgen.
- National Palliative Care Survey 2009-2010 (Ministry of Health).
- CHL (Palliative Care Unit and Support team CHL): Dr Frederic Fogen;
- Hellef Doheem, HELP.
- CHdN: Dr Frank Jacob (Support and Care);
- CHEM (Palliative Care Unit, Chemotherapy Day Clinic): Dr Bernard Thill (Only Support)
- HAUS OMEGA - OMEGA 90

Additional comments:

- Approximately 18 volunteers offer their services to Haus Omega (8am to 8pm).
- Only one hospital palliative care support team (CHL) is officially recognized by the Ministry of Health.
- Only one mixed palliative care support team (CHdN) is officially recognized by the Ministry of Health.
- Three palliative care units in tertiary hospitals are officially recognized by the Ministry of Health. Only one palliative care unit (CHEM) is fully independent, the others are connected to another department. In addition to the three palliative care units listed, another one exists with 10 beds; this unit does not have a palliative care physician and the ten beds are used for non-palliative care patients when required.
- There is a volunteer hospice team in the inpatient hospice.
- Haus Omega opened in September 2010.

Palliative care services for children:

A taskforce "palliative care for children" started in October 2012 at the CHL.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|-------------|--|
| 1990 | Omega 90 begins to develop the palliative care culture in Luxembourg. |
| 1998 | The term “palliative” appears for the first time in health policy; the first time in a policy about nursing (“règlement grand-ducal du 21 janvier 1998 portant sur l'exercice de la profession d'infirmier”), and several months later in a law about hospitals (“loi du 28 août 1998 sur les établissements hospitaliers”). |
| 2005 | The Ministry of Family agrees to fund the construction of the first hospice in Luxembourg (to be built by Omega 90 within the next two years). |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- The law on palliative care, living wills and time allocated to accompany a parent at the end of life (March 16th 2009).
- Omega 90 opened the first hospice in Luxembourg (15 beds) on the 15th September 2010. The hospice is recognized as a specialized hospital and financed until December 2010 by the Ministry of Family; since January 2011 it has been financed by the Ministry of Health (Caisse Nationale de Santé).
- Creation of the Luxembourg Association of Palliative Care Physicians – (ALMP) (2012); recognized by the EAPC.
- Creation of a palliative care platform (2012), under the initiative of Omega 90, gathering hospitals, elderly care homes and home care services, to discuss the main problems and suggest solutions to the Ministry of Health and the Ministry of Family.

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: There are five general hospitals in Luxembourg. Since 1994, one hospital has had an autonomous palliative care inpatient unit with 12 beds (it was adapted in 2001). Three hospitals each have a small palliative care inpatient unit with six beds but they are not autonomous (they share the night shift with a ward of internal medicine). One hospital tries to deliver palliative care to every patient (but is having difficulty in developing a mobile palliative care unit) (CHEM has 10 beds; CHL has five beds and CHDN has six beds).
- Nursing homes: A «règlement grand-ducal», stated that 40% of the employees in elderly homes and home care services have to attend a 40 hours palliative care course (with the agreement of the Ministry of Family since 2009) – Omega 90 has trained approximately 1500 health care professionals on the 40 hours palliative care course. – some nursing homes have already trained 90% of their staff, but there remains a great difference between homes willing to integrate palliative care in their daily business and others that just train their staff because of the stipulation by the Ministry of Family.
- Residential homes for the elderly: Luxembourg has very few residential homes for the elderly – there are mainly nursing homes/integrated centers for elderly persons, where people can remain even if they are ill or dying.
- Other community settings: Luxembourg has two large home care services: Hellef Doheem; and Help. These are second-level teams, trained to help their first-level colleagues in difficult situations. The Ministry of Family pays 150€/patient/day to sustain these services.

Expansion from a focus on cancer patients to address the needs of ‘non-cancer’ patients:

- There has been some expansion from a focus on cancer patients to address the needs of ‘non-cancer’ patients but there remains a lot of work to be done.
- Omega 90 attempts to prepare care homes to consider that elderly people at the end of life to have a right to die quietly and remain in their setting; the same principle applies to institutions for mentally or physically disabled persons. It is the same for neurological problems, but there remains a lot to do for persons who have chronic heart, lung or kidney failure.

Perceived barriers to the development of hospice and palliative care:

- Underdevelopment of continuous medical education.
- No law on palliative care education for health care providers.
- Civil society is not able to talk about suffering and death.
- The law on euthanasia.
- No national register for palliative care patients.
- No national end of life observatory.
- Palliative medicine is not recognized as a medical specialisation.
- The health system itself.

Perceived opportunities for the development of hospice and palliative care:

- The Law of palliative care (2009)
- The interest of (mainly) nurses for the provision of palliative care courses at the second and third level of education.
- The presence of a young physician trained in palliative care at one of the main hospitals in Luxembourg (and interested in raising palliative care on the medical agenda).

Other issues relevant to the development of hospice and palliative care:

The creation of the “IWAP”, an Interregional Palliative Care Academy for Continuous Education in Palliative Care by Omega 90, the LAG (Landesarbeitsgemeinschaft Hospiz Saarland) and Caritasverband Westeifel from Rheinland-Pfalz; a European Union supported project that has been working since 2009 for continuous education in the “Great Region” – Luxembourg and Germany (www.iwap-care.lu).

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- Association for Palliative Care OMEGA 90 was formed in 1990; it has a website (www.omega90.lu) and is representative of the whole country (but is not a member of the EAPC).
- Association for Palliative Medicine in Luxembourg (Association Luxembourgeoise de Médecine Palliative (ALMP)) was formed in 2011; a website is in the process of being developed. The association is not representative of the whole country (but is a member of the EAPC).

Directory or catalogue of palliative care services:

- Printed version: Brochure Soins palliatifs (2010) in French, German and Portuguese languages.
- Online version: www.sante.lu; www.cns.lu (2011).

Congresses, scientific meetings or scientific journals in palliative care:

IWAP (Interregional Palliative Care Academy) host 4-6 meetings each year, attended by approximately 20-40 healthcare professionals (www.iwap-care.lu).

Palliative care research capacity:

Researchers include: CHL, Department of Palliative Care, fogen.frederic@chl.lu.

Palliative care collaboration:

- There are official partnerships for volunteers between: OMEGA 90 and CHEM; OMEGA 90 and CHL; and OMEGA 90 and HK (Oncology);

- Pioneers include: OMEGA 90 was founded in 1990 by Caritas, Red Cross and Amperas (federation of all the local associations for elderly people in Luxembourg). In 2001, the two main home care services and the National Cancer Foundation joined Omega 90. Since it was formed, Omega 90 has developed: volunteering in palliative care (130 hours training and supervision); a department to accompany people in bereavement; a department for vocational training of healthcare professionals according to the principles of EAPC (2004); an inpatient hospice with 15 beds (September 2010).
- ALMP is an association of (six) doctors who have graduated in palliative care (recognized by the EAPC).
- World initiative: OMEGA 90 (in conjunction with CHL) organizes celebrations on World Hospice and Palliative Care Day.

Worldwide palliative care alliance level of development:

3B (Generalized palliative care provision): However, there is limited support provided by the Ministry of Health, limited availability of morphine and other strong painkillers because of burdensome administrative procedures and limited sources of funding available.

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- In 2006, Omega 90 adopted the recommendations of the EAPC for continuous education for healthcare professionals (on three levels) and also for volunteers.
- Several elderly care homes and home care services have adopted the recommendations of Omega 90 (officially recognized by the Ministry of Family) and created 40 hours continuous palliative care education for employees.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: A palliative care course is included in GP education in Luxembourg.
- Nursing: The length of nursing education has increased from three to four years, but there are no nursing teachers educated in palliative care.
- Social work: Unknown
- Other professions: Unknown

Specific developments in post-graduate palliative care education initiatives:

- Medicine: A 40-hour course of palliative care has been developed by "Alformec" (continuous education for physicians) – approximately 100 GP's have attended the course. IWAP has also developed an interregional 40-hour course for German and Luxembourg GP's (but it is difficult to have details of this course published by the Luxembourg GP's association).
- Nursing: Omega 90 has offered the only palliative care course for healthcare professionals since 1993 (160 hours); approximately 500 healthcare professionals have been trained (no physicians). Since 2010, Omega 90 has offered a 250-hour course for healthcare professionals (following the 160-hour course); approximately 70 participants are currently registered on this course.
- Social work: See above.
- Other professions: See above.

Translation of palliative care documents or other materials:

EAPC recommendations for nurses (2004).

Initiatives to develop healthcare professional leadership in palliative care:

There is no information available at this time.

Officially recognized medical certification:

After the palliative care law was passed in 2009, a proposal of vocational training (40 hours/160 hours training) for physicians and health care professionals was proposed (but it is not yet officially recognized).

Capacity of palliative care workforce training in Universities and Medical Schools:

- Luxembourg has no medical schools and all doctors are trained in neighbouring countries.
- There is the possibility of undertaking a GP specialization course in Luxembourg (three years).
- There are no Professors of Palliative Medicine in Luxembourg.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

There is no information available at this time.

Developments/opportunities/barriers relating to the accessibility of essential medications:

There is no information available at this time.

Developments/opportunities/barriers relating to the affordability of essential medications:

There is no information available at this time.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

There is no information available at this time.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- The law on palliative care and living wills enables a family member to accompany a parent at the end of life (40 hours, paid for by social security) (March 16th 2009).
- Ministry of Family: 40% of the employees of nursing homes are to be trained on the 40-hour palliative care course (December 2009).

The impact of these policy changes and ways in which they have been important:

- Omega 90 organizes conferences in order to familiarize civil society with the new palliative care law
- Omega 90 has developed a "living will" and offers free consultation in this area (a lot of people have accepted this offer).

Development of a national palliative care consensus:

The law on palliative care (2009).

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

Significant meetings occurred between July and September 2009, with the Ministry of Health, the Ministry of Family and the Ministry of Education (and other stakeholders in medicine and palliative care) in order to prepare a consensus about continuous palliative care education for health care professionals (no official result to date).

Development of an advocacy framework for integrating palliative care into the health care system:

There is no information available at this time.

Strategies to improve political awareness and government recognition of palliative care:

The creation of the first hospice in Luxembourg has increased awareness of palliative care in the Ministry of Health.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

- Omega 90 has received more donations since the opening of "Haus (house) Omega".
- CHL and CHEM units are funded by donors.

Involvement with the European Union in relation to hospice and palliative care initiatives:

IWAP (Interregional Palliative Care Academy) is a European Union funded project operating since 2009 in partnership with Germany (Saarland and Rheinland-Pfalz) for education and training of doctors and other healthcare professionals (www.iwap-care.lu).

Development of initiatives framing palliative care as a 'human right':

The IAHP-C-WPCA Joint Declaration and Statement of Commitment to Palliative Care
There is no information available at this time.

General legislation relating to palliative care:

- Loi relative aux soins palliatifs, à la directive anticipée et à l'accompagnement en fin de vie (16.03.2009).
- Loi sur l'Euthanasie et l'Assistance au Suicide (16.03.2009).
- Legislation relating to palliative care, living wills and company at the end of life.
- Legislation about euthanasia and medically-assisted suicide.
- www.legilux.public.lu/leg/a/archives/2009/0046/ao46.pdf

Published national documents relating to palliative care standards and norms:

There is no information available at this time.

National Plan or Strategy of Palliative Care:

There is no information available at this time.

National Cancer Control Strategy:

There is no information available at this time.

National HIV/AIDS Strategy:

There is no information available at this time.

National Primary Health Care Strategy:

There is a National Primary Health Care Strategy but it does not contain an explicit reference to palliative care provision.

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

There is no information available at this time.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- An additional prescription must be signed by a GP or hospital doctor.
- Strong opioids are prescribed for a maximum of 21 days of treatment (oral) or for seven days (injectable).
- Five main opioids are available: morphine; hydromorphone; oxycodone; fentanyl; buprenorphine.
- Fentanyl nasal spray is mostly unavailable for outpatients.
- Oxycodone and naloxone are reserved for inpatients only.
- Levomethadone is not available.

Funding of palliative care services:

- There is no payment required for palliative care consultation or hospitalisation.
- Cancer patients can be reimbursed 100% for the cost of medication (on demand); non-cancer patients are reimbursed for a maximum 80% for the cost of medication.
- The Ministry of Family pay 150€/day/patient for home care services providing specialized palliative care.

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006**Change in public awareness or perception of hospice and palliative care:**

There is no information available at this time.

Major public discussion, debate or controversy about hospice and palliative care:

There is no information available at this time.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

- There have been approximately 50 public conferences about the law of palliative care in Luxembourg, attended by approximately 2000 people.
- Some articles have been published in the media about "Haus Omega" and there have been some TV documentaries also.

Hospice or palliative care 'success' stories:

- The palliative care law of 2009.
- The opening of "Haus Omega" and the ongoing progress of this institution (www.omegago.lu).
- The document "living will" provided by Omega 90.
- In July 2012, the first public document about the activities of Omega 90 was produced.
- The creation of the ALMP (Luxembourg Association of Palliative Care Physicians).

Initiatives seeking the legalisation of euthanasia or assisted dying:

The Law of 16th March 2009 referring to the impunity of euthanasia and assisted suicide for physicians (voted on the same day as the palliative care law) is a very restrictive law containing many conditions of form and content. Unfortunately, society does not easily differentiate between palliative care and euthanasia (although once the difference is explained, most citizens understand). Most people want to die without pain and their first request is often for something to enable them to "die fast and without pain".

Omega 90 opened the first hospice in Luxembourg (15 beds) in 2010. The hospice is recognized as a specialized hospital and was financed initially by the Ministry of Family; since 2011 it has been financed by the Ministry of Health

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

- Palliative care is developing in Luxembourg but a law relating to continuous palliative care education for all health care professionals (including physicians) is required.
- The Ministry of Family policy that 40% of employees be trained on a 40-hour palliative care course by 2015 and that some employees be trained on a 160-hour palliative care course is a step forward.

Most significant issues facing hospice and palliative care in the next three years:

- A law considering palliative care courses for all health care professionals (40 hours and 160 hours) from the Ministry of Health is required.
- Define palliative care health acts (physicians, nurses, social workers, psychologists, and other health carers) and arrange for these acts to be funded by the National Health Insurance and the Insurance for Dependence.
- Create a “national platform” of palliative care, with hospitals, elderly care homes and home care services, in order to inform the Luxembourg government and “everyone who is interested” about palliative care (facts and evidence-based information - Omega 90 is working on this issue).

Implications for palliative care relating to the current economic crisis:

It is very important to inform citizens about their right to palliative care and to convince the government that effective palliative care can save a lot of money for the community and a lot of suffering for the individual and that a “good” bereavement does the same for the community and the relatives.

References

There are no known publications at this time.

Malta¹

NATIONAL ASSOCIATION/KEY CONTACT

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Yoram Singer

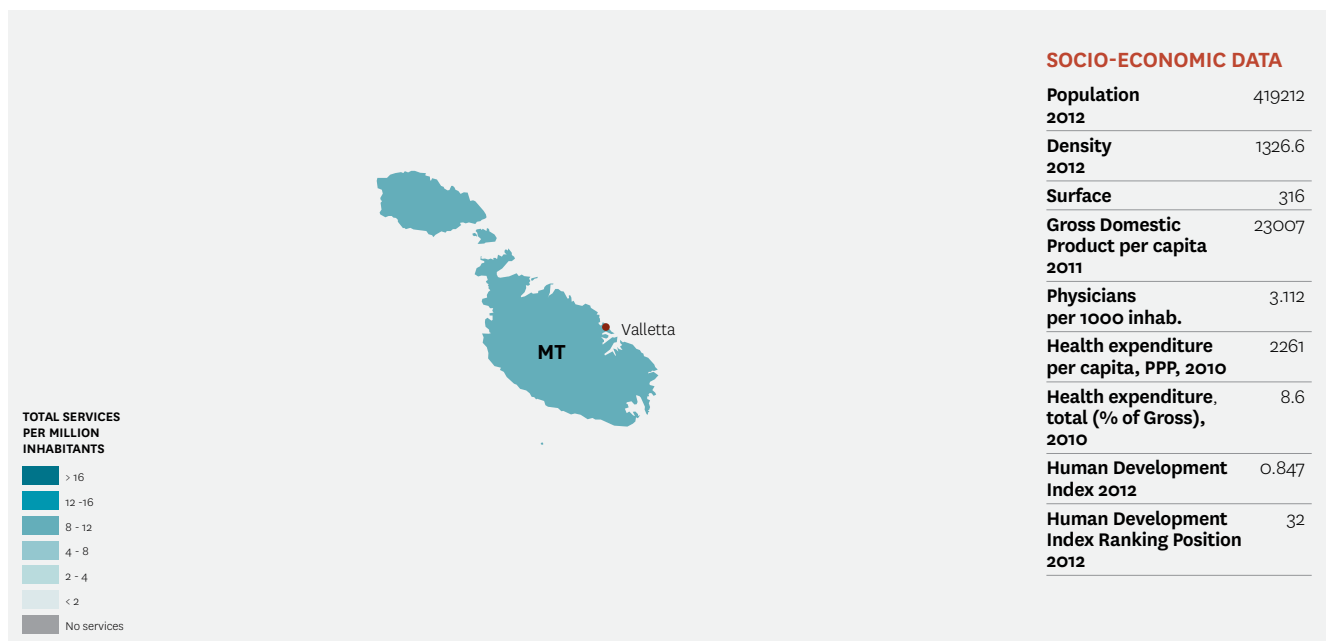
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 1 |
| Hospital palliative care support team | 1 |
| Home palliative care support team | 1 |
| Mixed palliative care support team | 1 |
| Palliative care units in tertiary hospitals | 1 (10) |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 0 |
| Day hospice/day care centre | 1 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

Dr JP Tabone

Additional comments:

- Hospice Malta operates the only volunteer hospice team in Malta.
- Hospice Malta also operates in the acute general hospital.
- Hospice Malta provides community palliative care services in Malta.
- There are palliative care beds in the Oncology and Dermatology wards in Boffa Hospital.

Palliative care services for children:

- There is one paediatric volunteer hospice team; one paediatric hospital palliative care support team (four beds); one paediatric home palliative care support team; and one paediatric palliative care unit in a tertiary hospital (four beds).
- Paediatric palliative care beds are part of the Oncology ward in the acute general hospital (there is only one acute general hospital in Malta).

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|------|--|
| 1989 | The Malta Hospice Movement is established with the aim of introducing hospice/palliative care to the Maltese Islands. |
| 1990 | The Malta Hospice Movement is twinned with Hayward House Macmillan Palliative Care Unit, Nottingham, England, providing a solid foundation for the organisation. |
| 1998 | A pain clinic is set up in the State general hospital to manage chronic pain. |
| 2005 | Fentanyl patches are introduced into the private health sector. |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- The development of the hospital/home palliative care support team.
- Palliative care is now provided for patients with cardiac and respiratory conditions, cancer and Motor Neurone Disease.
- The development of palliative care at the Oncology Hospital in Malta (10 beds).
- Progress in palliative care education for both Hospice Malta staff and other healthcare professionals (especially family doctors).

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: A palliative care team has been established by Hospice Malta in the acute teaching hospital.
- Nursing homes: Lectures relating to the provision of palliative care in nursing homes have been delivered.
- Residential homes for the elderly: Lectures relating to the provision of palliative care in residential homes for the elderly have been delivered.
- Other community settings: Lectures and presentations relating to the provision of palliative care in various local communities have been delivered.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

Since 2009, palliative care has been provided to patients in the community with heart failure and respiratory diseases. This care has been provided by Hospice Malta (but not yet by the Maltese Health Department).

Perceived barriers to the development of hospice and palliative care:

- Lack of financial resources.
- The failure of politicians to acknowledge that end-of-life care should be provided to all patients irrespective of their disease.
- Insufficient space at Hospice Malta to expand and therefore provide a more extensive palliative care service.

The home palliative care support team has been developed and palliative care is now provided at the Oncology Hospital (10 beds). Palliative care is provided for patients with cardiac and respiratory conditions, cancer and Motor Neurone Disease

Perceived opportunities for the development of hospice and palliative care:

- Recognition of palliative care services provided by Malta Hospice in the community by medical professionals and the general public.
- An ongoing educational programme in palliative care for staff and other healthcare workers (especially family doctors).
- Malta Hospice's total acceptance of the 2006 WHO directives to provide end-of-life care for all patients.

Other issues relevant to the development of hospice and palliative care:

Malta Hospice has updated its education policy and is encouraging its medical and nursing staff to obtain an MSc (UK) in end-of-life care; to date, approximately 35% of staff have achieved this objective. Every staff member of the care team has attained the European Certificate in Essential Palliative Care from the UK.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

There is no information available at this time.

Directory or catalogue of palliative care services:

There is no information available at this time.

Congresses, scientific meetings or scientific journals in palliative care:

There are various congresses held on an annual basis with each congress attended by approximately 150 participants.

Palliative care research capacity:

Researchers: Dr Jurgen Abela (Hospice Malta).

Palliative care collaboration:

- There is twinning between Hospice Malta and Hayward House Macmillan Continuing Care Unit (involving mutual cooperation as the need arises).
- There is educational collaboration between Hospice Malta and Princess Alice Hospice, Esher, UK.
- Palliative care pioneers include Hospice Malta (formed in 1989 as The Malta Hospice Movement): Hospice Malta is a voluntary organisation inspired by Christian values. It exists to provide and promote the highest standards of palliative care for all persons with cancer, motor neurone disease and other terminal diseases. It also aims to help and support their families and carers.
- Hospice Malta organises an event every year to promote World Hospice and Palliative Care Day (cultural events/fundraising/concerts, etc.).

Worldwide palliative care alliance level of development:

4A (Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- Hospice Malta delivers palliative care lectures to medical students, nursing students and trainee family doctors.
- Hospice Malta hosts annual conferences for healthcare professionals.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Delivery of lectures by Hospice Malta.
- Nursing: Delivery of lectures by Hospice Malta and placements at the hospice.
- Social work: Delivery of lectures by Hospice Malta and placements at the hospice.
- Other professions: There is no information available at this time.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: Trainee family doctors have placements at Hospice Malta and attend various hospice conferences.
- Nursing: Nurses attend various hospice conferences.
- Social work: Social workers attend various hospice conferences.
- Other professions: A variety of other healthcare professionals attend various hospice conferences.

Translation of palliative care documents or other materials:

No translation of palliative care documents or other materials is necessary because English is Malta's primary study language.

Initiatives to develop healthcare professional leadership in palliative care:

A palliative care consultant has been appointed.

Officially recognized medical certification:

Since 2003, palliative medicine has been recognized as a medical specialty in Malta, consisting of a minimum of six years supervision by a specialist and culminating in a relevant post-graduate degree. To date, there are four professionals that have been accredited in this way (by Grandfather Rights). The accreditation process is certified by the Specialist Accreditation Committee of Malta.

Capacity of palliative care workforce training in Universities and Medical Schools:

- Malta has one medical school; palliative care is a mandatory component (estimate - personal experience).
- There are an estimated two "other professors" in palliative medicine (part-time lecturers who deliver the Oncology module).

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

There are no new developments relating to the availability of essential medications, except for the availability of levomepromazine (though this is somewhat limited).

Developments/opportunities/barriers relating to the accessibility of essential medications:

- At present, no changes relating to the accessibility of essential medications have been enacted. To access essential medications, patients need to have approval from a hospital-based doctor.
- Bureaucracy is a major problem for community-based practitioners; for example, an excessive reliance on hospital counter-prescribing is a burden to providing community-based treatment.

Developments/opportunities/barriers relating to the affordability of essential medications:

Morphine is relatively cheap in Malta; other medications commonly used are also not particularly expensive (with the possible exception of Pregabalin and Gabapentin).

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

Hospice Malta provides educational initiatives for various healthcare professionals where 'opiophobia' is sometimes discussed. However, no initiative has been developed that focuses specifically on addressing this issue.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

There has been progress in palliative care education for both Hospice Malta staff and other healthcare professionals (especially family doctors). Palliative care lectures have been delivered in nursing homes and residential homes for the elderly

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

Malta Hospice has attempted to establish a policy on prescribing DDAs but the response from the Maltese government to date has been negative.

The impact of these policy changes and ways in which they have been important:

There is no information available at this time.

Development of a national palliative care consensus:

A palliative care ward with ten beds has been opened at the National Oncology Hospital (admitting cancer patients only).

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

A number of very informal meetings have taken place with stakeholders and policy makers to develop palliative care strategies.

Development of an advocacy framework for integrating palliative care into the health care system:

An advocacy framework for integrating palliative care into the health care system has been developed.

Strategies to improve political awareness and government recognition of palliative care:

There have been educational initiatives and meetings organised with relevant parties to improve political awareness and government recognition of palliative care.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

There have been palliative care funding initiatives by Hospice Malta and various donors.

Involvement with the European Union in relation to hospice and palliative care initiatives:

There is no information available at this time.

Development of initiatives framing palliative care as a 'human right':

As far as Hospice Malta is aware, the necessary framework to consider palliative care as a 'human right' has not been included in the manifestoes of the two leading political parties in Malta.

General legislation relating to palliative care:

Legislation does not specifically relate to palliative care but medical provision in general.

Published national documents relating to palliative care standards and norms:

There is no information available at this time.

National Plan or Strategy of Palliative Care:

There is no information available at this time.

National Cancer Control Strategy:

There is a National Cancer Control Strategy that mentions increasing the number of palliative care services (although the focus is predominantly on screening and the prevention of cancer).

http://www.sahha.gov.mt/showdoc.aspx?id=862&filesource=4&file=A_NATIONAL_CANCER_PLAN_Feb_2007.pdf

National HIV/AIDS Strategy:

There is no information available at this time.

National Primary Health Care Strategy:

There is no information available at this time.

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

The Maltese Health Department is responsible for all health provision in Malta (they are therefore responsible for the delivery of palliative care services).

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

Hospice Malta conducts internal audits.

Opioid legislation/Pain guidelines:

Each patient requiring opioids in Malta needs a "control card". Once in possession of this card, a patient needs a specific prescription from a doctor each month. All cancer patients are entitled to receive opioids free of charge. Opioids can also be purchased in the community (but require a prescription as described above).

Funding of palliative care services:

- There is no payment required for palliative care consultation or hospitalisation.
- There is a list of diseases (including cancer and HIV) which entitles patients to free medicines (for other diseases, partial payment may be required).

There has been increased recognition by medical professionals and the general public of palliative care services provided by Malta Hospice in the community. Malta Hospice has promoted the 2006 WHO directives to provide end-of-life care for all patients

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

Public awareness and perception of hospice and palliative care has been greatly improved as a result of the continuous educational programmes conducted by Hospice Malta.

Major public discussion, debate or controversy about hospice and palliative care:

There is no information available at this time.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

There have been many initiatives that seek to broaden awareness and understanding of hospice and palliative care; there has been frequent exposure in the media – TV/radio – and also in newspapers/journals.

Hospice or palliative care ‘success’ stories:

- The opening of the new palliative care ward.
- The building of an oncology and palliative care unit as part of the acute hospital.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is no information available at this time.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

- The Maltese Government is building a new oncology and palliative care unit for both adults and children as part of the main acute hospital.
- Hospice Malta is planning to build a purpose-built palliative care unit to include: a day centre; outpatient unit; community service; and inpatient unit (to provide end-of-life care for all patients).

Most significant issues facing hospice and palliative care in the next three years:

Addressing the palliative care needs of patients suffering from Alzheimer’s disease and HIV/AIDS. If the needs of these groups of patients are to be incorporated in hospice care, it may be necessary to increase the palliative care bed capacity in the new building.

Implications for palliative care relating to the current economic crisis:

- Currently, the financial situation is bleak as contributions from donors have decreased and funds raised from activities have also been reduced. In addition, sufficient funding has not been provided by the Maltese government.
- Future challenges include persuading the Maltese government to meet its obligations in providing palliative care for the public and making them fully aware of the need for increased funding if they require that obligation to be adequately fulfilled.

References

Naudi T. 2002. “Global perspective. Family support: a summer holiday programme for Maltese children”. *Palliat Med*; 16(2):159-61.

Jacqueline H Watts and Jurgen Abela. March-April 2011. “European insight: Malta Hospice Movement: palliative care in a tightly knit community”. *European Journal of Palliative Care*, Volume 18 Number 2, 97-99.

Future challenges include persuading the Maltese government to meet its obligations in providing palliative care for the public and making them fully aware of the need for increased funding if they require that obligation to be adequately fulfilled

Montenegro¹

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | ○ |
| Hospital palliative care support team | ○ |
| Home palliative care support team | ○ |
| Mixed palliative care support team | ○ |
| Palliative care units in tertiary hospitals | ○ |
| Palliative care units in non-tertiary hospitals | ○ |
| Inpatient hospice | ○ |
| Day hospice/day care centre | ○ |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:
Jadranka Lakicevic

Additional comments:

The primary level of health care is responsible for the delivery of home-based palliative care (family doctors and supportive centres).

Palliative care services for children:

There is no information available at this time.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

There is no information available at this time.

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- The reform of the health care system commenced in 2004; reform of the hospital sector is still in process.
- The primary level of health care is responsible for the delivery of home-based palliative care (family doctors and supportive centres, including hospitals).

Overall progress in hospice and palliative care:

Progress in hospice and palliative care remains the same.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: There is no information available at this time.
- Nursing homes: There is no information available at this time.
- Residential homes for the elderly: The home for elderly people 'Grabovac' (situated in Risan) is the only residential home in Montenegro that provides any form of palliative care.
- Other community setting: There is no information available at this time.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

There is no information available at this time.

Perceived barriers to the development of hospice and palliative care:

- A palliative care needs assessment is required due to the absence of accurate and reliable data about patients requiring palliative care.
- Currently, palliative care in Montenegro focuses predominantly on the physical aspects of care; other aspects of support for the patient and family (social, psychological, emotional, spiritual) are not considered.
- There are no existing practitioners who are educated or trained in palliative care.

Perceived opportunities for the development of hospice and palliative care:

- Accessing international expertise and experience in order to provide palliative care education and training for all healthcare professionals.
- Establishment of inter-sectoral cooperation within the healthcare system (and also between the healthcare system and other systems).
- Raising awareness about palliative care (for example, mission and achievements) amongst healthcare professionals, policy makers, patients, their families and the general public.

Other issues relevant to the development of hospice and palliative care:

Lack of international support for the development of palliative care in Montenegro (although it has been requested on many occasions).

The reform of the health care system commenced in 2004 and is still in process. The (2010) Master Plan of Health Care Development in Montenegro stipulates that special attention will be given to the establishment of palliative care

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

There is no information available at this time.

Directory or catalogue of palliative care services:

There is no information available at this time.

Congresses, scientific meetings or scientific journals in palliative care:

There is no information available at this time.

Palliative care research capacity:

There is no information available at this time.

Palliative care collaboration:

There is no information available at this time.

Worldwide palliative care alliance level of development:

There is no information available at this time.

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

A number of doctors have undertaken short-term palliative care education initiatives.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: There is no information available at this time.
- Nursing: There is no information available at this time.
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: There is no information available at this time.
- Nursing: There is no information available at this time.
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Translation of palliative care documents or other materials:

There is no information available at this time.

Initiatives to develop healthcare professional leadership in palliative care:

There is no information available at this time.

Officially recognized medical certification:

There is no information available at this time.

Capacity of palliative care workforce training in Universities and Medical Schools:

Montenegro has two medical schools (no palliative care component); there are no Professors in Palliative Medicine (Source: Ministry of Education).

The strategy for optimization of secondary and tertiary health care levels within the National Action Plan (2011) states that palliative care will be applied to the treatment and care of patients with chronic diseases and those in the terminal stage

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

There is slight improvement relating to the availability of essential medications. Currently in Montenegro, oral morphine in the form of liquid and parenteral morphine is available, while the list of essential medicines features transdermal fentanyl for the treatment of strong cancer pain (although there are no data available about the consumption of opioids in the treatment of strong cancer pain).

Developments/opportunities/barriers relating to the accessibility of essential medications:

There is slight improvement relating to the accessibility of essential medications.

Developments/opportunities/barriers relating to the affordability of essential medications:

There is slight improvement relating to the affordability of essential medications.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

There is no information available at this time.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

All patients are covered by obligatory health insurance, irrespective of their economic situation.

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- The (2010) Master Plan of Health Care Development in Montenegro stipulates that special attention will be given to the establishment of palliative care.
- The strategy for optimization of secondary and tertiary health care levels within the National Action Plan adopted in July 2011 states that palliative care will be applied to the treatment and care of patients with some chronic diseases and those in the terminal stage; the plan also states that palliative care should be implemented within standard care rather than as a “special service”, and must become an integral part of the Montenegrin healthcare system (at all levels and across all specialties).

The impact of these policy changes and ways in which they have been important:

These policy changes have not yet been implemented, so it is not possible to evaluate their impact.

Development of a national palliative care consensus:

The strategic framework for developing palliative care exists within the Master Plan of Health Care Development (2010) and the strategy for optimization of secondary and tertiary health care levels; however, there are still no palliative care frameworks, standards, guidelines or legislation.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

There is no information available at this time.

Development of an advocacy framework for integrating palliative care into the health care system:

There is no information available at this time.

Strategies to improve political awareness and government recognition of palliative care:

Palliative care is recognized as such, but the process of development is dependent upon the reform of the health care system.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

There has been some funding for the home for elderly people “Grabovac” in Risan. The home received support from the Montenegrin Government, UNHCR (and some support from a Dutch donor) for construction of the facility, and for the introduction of quality standards.

Involvement with the European Union in relation to hospice and palliative care initiatives:

There is no information available at this time.

The National Action Plan (2011) states that palliative care should be implemented within standard care rather than as a “special service”, and must become an integral part of the Montenegrin healthcare system (at all levels and across all specialties)

Development of initiatives framing palliative care as a ‘human right’:

Initiatives framing palliative care as a ‘human right’ are insufficiently developed in Montenegro.

General legislation relating to palliative care:

Legislation relating to palliative care is in process (www.mzdravlja.gov.me/).

Published national documents relating to palliative care standards and norms:

There is no information available at this time.

National Plan or Strategy of Palliative Care:

There is no information available at this time.

National Cancer Control Strategy:

There is no information available at this time.

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy but it does not contain an explicit reference to palliative care provision.

National Primary Health Care Strategy:

There is no information available at this time.

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

There is no information available at this time.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- The manner of prescribing opioids for adequate pain treatment in oncological patients is somewhat restricted: double prescription is necessary, while the opioid may only be prescribed by the chosen doctor on the basis of a report produced by a medical specialist. Opioids are only available in the public pharmacies and in hospitals.
- The National Clinical Guideline “Drug therapy of chronic cancer pain” is available from 1st July 2012 on the website of the Ministry of Health (www.mzdravlja.gov.me/).

Funding of palliative care services:

There is no payment required for palliative care consultation, hospitalisation or medication.

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:
There is no information available at this time.

Major public discussion, debate or controversy about hospice and palliative care:
There is no information available at this time.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:
Some articles referring to chronic cancer pain have been published.

Hospice or palliative care 'success' stories:
"Grabovac" palliative care facility in Risan.

Initiatives seeking the legalisation of euthanasia or assisted dying:
There is no information available at this time.

Palliative care incorporation into the healthcare system is based on the needs of the system: an aging population; a high percentage of chronic non-communicable diseases; the structure of morbidity and mortality; and in line with projected goals on reform of the healthcare sector

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

- Palliative care incorporation into the healthcare system is based on the needs of the system: an aging population; a high percentage of chronic non-communicable diseases; the structure of morbidity and mortality; and in line with projected goals on reform of the healthcare sector.
- Key action points include; an assessment of the needs of oncological patients for palliative care; training of health service providers at different levels of health care, including community and caregivers who are involved in the provision of services; a review and amendment of the regulations which restrict the use of opioid analgesics (including oral morphine) in order to make them more available and accessible and create opportunities for trained doctors to prescribe them; review the list of essential medicines and make them more available and accessible; establish coordination and referral mechanisms for patients who need palliative care; elaborate standards for palliative care and disseminate them throughout the healthcare system (public and private sector); develop educational programs for inclusion in undergraduate and post-graduate curricula at the faculties of medicine and nursing schools; develop public awareness-raising campaigns (www.mzdravlja.gov.me).

Most significant issues facing hospice and palliative care in the next three years:

- In Montenegro, there is no data available for assessing the needs of oncological patients.
- Organized palliative care does not currently exist in Montenegro; it is provided as a part of the everyday activities and usual practices of medical staff at all levels of health care and predominantly focuses on the control of pain and other physical symptoms of advanced malignant disease.
- Medical staff are not specially trained to provide this type of care, with the exception of about 200 teams of chosen doctors who have been familiarized with the basic principles of palliative care and therapy of chronic cancer pain (in line with WHO fundamental principles) during the course of additional training programmes implemented within the reform of the primary level of healthcare.
- Other forms of support which are related to the social, psychological and existential dimension of illness are not currently provided to patients and their families in Montenegro. In addition, the general public is not sufficiently informed about the importance of palliative care for oncological patients.
- The majority of oncological patients are treated by a family doctor, with occasional consultations with oncologists, surgeons and doctors specialized in other fields. A holistic approach to the patient is not applied and there are no special services focused on meeting all the needs of the patient.

Implications for palliative care relating to the current economic crisis:
There is no information available at this time.

References

There are no known publications at this time.

Netherlands¹

NATIONAL ASSOCIATION

Palliactief, the Dutch Association for Professional Palliative Care

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T/F +31 (0) 30 6575 256
info@palliactief.nl
<http://www.palliactief.nl>
Professor Kris Vissers, CHAIR

KEY CONTACT

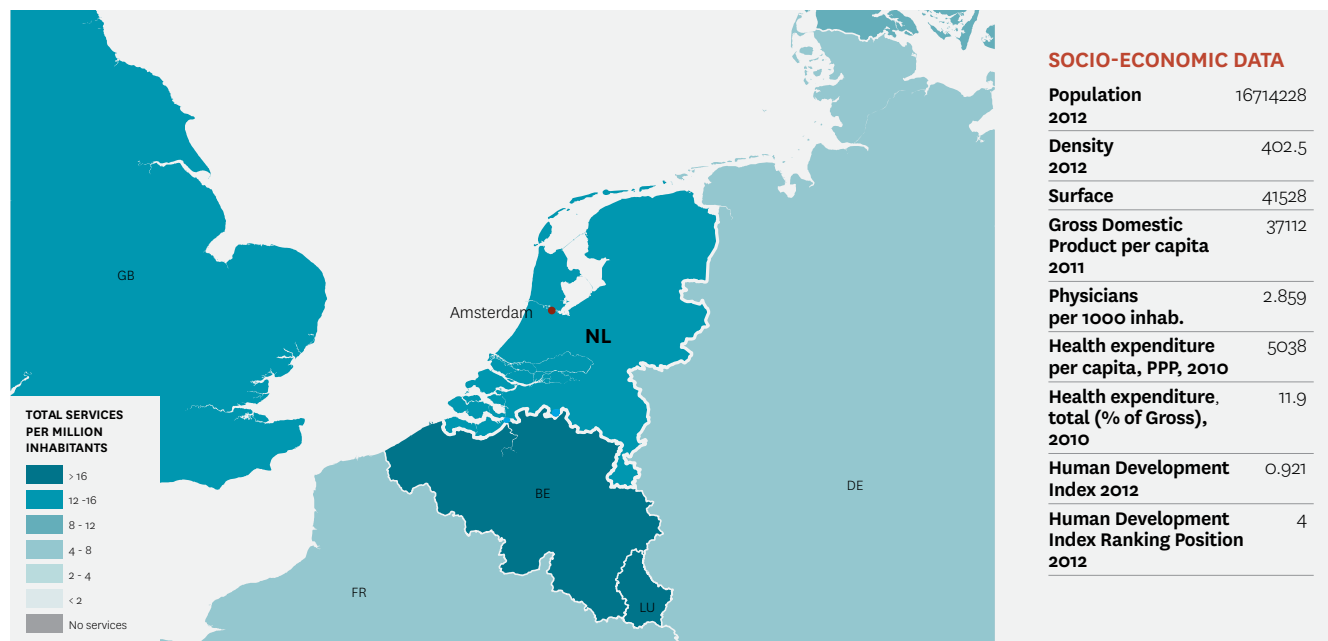
Marijke Wulp Policy advisor

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Groeneweg 21A, 3981 CK Bunnik, The Netherlands
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Additional information provided by:

José Weststrate

¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 61 (204) |
| Hospital palliative care support team | 0 |
| Home palliative care support team | 44 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 16 (50) |
| Palliative care units in non-tertiary hospitals | 141 (644) |
| Inpatient hospice | 55 (328) |
| Day hospice/day care centre | 29 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- www.netwerkpalliatievezorg.nl
- The 66 palliative care networks record the number of hospices in their own region and post it on their website (to maintain an accurate national record).
- <http://www.palliatief.nl/ZorgKiezen/Persoonvoorziening.aspx>
- <http://www.agora.nl/ZorgKiezen/Statistieken.aspx>

Additional comments:

- The number of hospital palliative care support teams has increased (but is unknown).
- There are 44 home palliative care support teams (consultation teams) that provide specialist advice (often by phone); most teams do not provide bed-side care (although a small number do). In addition, there are a large number of district nursing teams that provide home palliative care.
- There has been a strong growth in all types of palliative care services.
- Arianne Brinkman started a PhD project at Erasmus University MC Rotterdam in 2012 to study the benefits and costs of hospital palliative care support teams.
- There are almost no social workers in the consultant teams; they contain specialized physicians and nurses (and also other carers). Social workers form a minority.
- In all tertiary hospitals, patients can be admitted for specialised palliative care (but in most of these hospitals it is not provided in separate units).

Palliative care services for children:

There are seven paediatric inpatient hospices and a small number of paediatric day hospices/day care centres (number unknown).

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|------------------|---|
| 1993 | Four “bodies of knowledge of pain” are created. Their task is to improve the treatment of pain through developing research and education in the field of pain. |
| 1997-2003 | The Ministry of Health (VWS) initiates six centres for the development of palliative care, financed by the Dutch government for a six-year period. |
| 2002 | The Ministry of Health (VWS) funds AGORA as an independent information and communication centre for palliative care. |
| 2003 | The EAPC conference focuses attention on palliative care at the policy level, and within the health care organisations and professions. |
| 2004 | The NPTN (in partnership with AGORA) translate and distribute the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organization of palliative care). |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- Governmental policy regarding palliative care; for example, the Ministry of Health action plan for palliative care: Installation Platform Palliative Care (2006-2011).
- The merging of eight of nine Comprehensive Cancer Centers into IKNL (Comprehensive Cancer Center - the Netherlands) in 2011.
- There has been an increase in (and differentiation) of palliative care services.
- There are more “high-care” hospices (quality mark) (increased from 13 to 19) and more palliative care provision in nursing homes (two out of every ten nursing homes has created a hospice/palliative unit. The size of these units is different (mean 4.6 beds) For hospices the mean is 4.4 beds (<http://www.agora.nl/ZorgKiezen/Statistieken/Geschiedenis.aspxof>).
- The availability of 66 palliative care network organisations across the country; each one of them with one or more palliative care consultation service and unit.
- Four university palliative care expertise centers were set up and are working together as centres of excellence: Erasmus MC (Rotterdam); Free University Medical Center (Amsterdam); University Medical Center St. Radboud (Nijmegen); Utrecht Medical Center (Utrecht). In 2012, four new sites were initiated at Maastricht University Medical Center (Maastricht), Leids University Medical Center (Leiden), University Medical Center Groningen (Groningen), and Academic Medical Center Amsterdam (Amsterdam) (<http://www.nfu.nl/thema/palliatieve-zorg>).
- There has been an increase in palliative care educational and training opportunities in local, regional and national programmes.
- There has been an amelioration of national collaboration between all relevant organisations.
- V&VN PV (palliative care nurses organisation) is committed to developing palliative care in the Netherlands and has a broad target group (nurses and carers in palliative care and beyond) (<http://www.palliatievevzorg.venvn.nl/>).

Overall progress in hospice and palliative care:

Hospice and palliative care has improved in all parts of the Netherlands.

Development of hospice and palliative care in different health and social

care settings:

- Hospitals: An increasing number of hospitals are developing specialised palliative care consultation services.
- Nursing homes: More nursing homes are creating palliative care units (although most of them are relatively small in number - 1-2 beds). Specific progress has been made in nursing homes for psychiatric patients, and people with dementia.
- Residential homes for the elderly: The provision of palliative care has generally remained the same but some progress is being made in collaboration with palliative care networks.
- Other community settings: More attention is being paid to providing palliative care in the home care setting. Many Advance Care Planning projects are being developed in collaboration with general practitioners, community nurses and hospices.

Expansion from a focus on cancer patients to address the needs of ‘non-cancer’ patients:

- There has been more focus on people living with dementia, COPD and heart failure; also an increased focus on psychiatric patients and persons with a learning disability. ZonMw, the Netherlands Organisation for Health Research and Development, funds research on palliative care for patients with ALS, dementia, COPD and neurological diseases.
- Agora, the national Dutch support centre for palliative care, regularly organizes meetings relating to palliative care for non-cancer patients.
- A module of palliative care is being developed that can be used to provide specific forms of care to different patient groups.

Perceived barriers to the development of hospice and palliative care:

- The transfer from one healthcare organisation to another can be a problem (patient information is not always available 24 hours/7 days per week).
- Patients and the general public are not always familiar with the provision of palliative care.
- Primary caregivers are not sufficiently supported by palliative care specialists (there is no continuous access to palliative care).
- Palliative care is not included in undergraduate, postgraduate or specialist medical education programs.
- Palliative care is not always provided according to the relevant guidelines.

Perceived opportunities for the development of hospice and palliative care:

- The provision of palliative care earlier in the disease trajectory.
- The further implementation of palliative care in the hospital and home care setting.
- An increased focus on the provision of palliative care for non-cancer patients.

Other issues relevant to the development of hospice and palliative care:

There is a need for more financial unity between collaborating organisations and healthcare professionals.

There has been an increase in the number of hospices and more palliative care provision in nursing homes. In 2011, eight of nine Comprehensive Cancer Centers merged to become Comprehensive Cancer Center - the Netherlands

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- Agora, the National Center for Palliative Care (Agora, landelijk ondersteuningspunt palliatieve zorg) was formed in 2002; the association has a website (www.agora.nl) and is representative of the country on various topics (spiritual care, people with a learning disability, psychiatric patients, social work, day care, multidisciplinary support/home teams, public relations, provision of information for patients, professionals, and the general public).
- Palliatief (the national association of palliative care), was formed in 2010 as the scientific association for professionals in palliative care in the Netherlands. The association has a website (www.palliatief.nl).
- The Comprehensive Cancer Centers of the Netherlands (Integraal Kanker Centrum Nederland (IKNL)) was formed in 2011; the association has a website (www.iknl.nl) and is representative of the country on various topics (especially issues associated with cancer consultation and training).
- PalHAG, the general practitioners advisory group in palliative care (Huisartsen adviesgroep palliatieve zorg) was formed in 2012 and aims to support general practitioners in the delivery of palliative care and the implementation of standards of palliative care.

Directory or catalogue of palliative care services:

There is an online directory of palliative care services (<http://www.agora.nl/ZorgKiezen.aspx>); the first edition was posted online in 2003, the latest edition in 2013.

Congresses, scientific meetings or scientific journals in palliative care:

- The National Congress of Palliative Care is held biannually and is attended by approximately 350 participants.
- The Dutch-Flemish Congress is held every 18 months (alternately in the Netherlands and in Belgium); it is attended by approximately 100 participants.
- Board meetings of the EAPC and meetings of the EAPC Taskforce on Spiritual Care are sometimes held in the Netherlands.
- Many symposia for caregivers in palliative care are held in the Netherlands.
- The journal Netherlands-Vlaams Tijdschrift voor Palliatieve Zorg (Dutch-Flemish Journal of Palliative Care) is published three times a year.

Palliative care research capacity:

Centers of expertise in palliative care:

- VU medisch centrum (Amsterdam) (<http://www.vumc.nl/afdelingen/epz/>) Coordinator Dr. W.J.J. Jansen, Postbus 70571007 MB Amsterdam: tel: 003120 - 444 2933; fax: 020 - 444 4385. Wjj.jansen@vumc.nl
- Radboud University Nijmegen Medical Center, Department of Anesthesiology, Pain and Palliative Medicine, expertise center and ESMO designated center for oncological and palliative care; head of department, prof. dr Kris Vissers, Head of Research unit, ms dr. Yvonne Engels, Geert Grooteplein 10, 6500 HB Nijmegen, tel +31 24 3666318, - K.Vissers@anes.umcn.nl <http://www.umcn.nl/Zorg/Afdelingen/AnesthesiologiePijnenPalliatieveGeneeskunde/PalliatieveZorg/Pages/default.aspx>
- Erasmus MC (Rotterdam), (http://www.erasmusmc.nl/kenniscentrum_palliatieve_zorg), Chair Prof. Dr. C. C. D. van der Rijt, Postbus 5201, 3008 AE Rotterdam, tel. 003110-4391906. c.vanderrijt@erasmusmc.nl
- Universitair Medisch Centrum (Utrecht) (<http://www.umcutrecht.nl/subsite/cancercenter/Verwijzers/Themadossier-Palliatieve-zorg>) Chair Mw. dr. S. Teunissen, UMC Utrecht Cancer Center, Postbus 85500, Huispost nummer Str.3.1153508 GA Utrecht: tel 003188 - 75 508 19. SaskiaT@hospicedemeter.nl
- University Medical Center Groningen (Groningen), chair Dr. A.K.L. Reyners, Postbus 30.001, 9700 RB Groningen, tel 003150- 361 2370. a.k.l.reyners@int.umcg.nl
- Academic Medical Center Amsterdam, (Amsterdam), (<http://www.amc.nl>), Dr. B. Wanrooij, Postbus 22660 1100 DD Amsterdam, tel 003120-5669111 b.s.wanrooij@amc.uva.nl
- Leids Universitair Medisch Centrum (Leiden), (<http://www.lumc.nl>), chair Dr. Y.M. Van der Linden, LUMC, Postbus 9600, 2300 RC Leiden: tel. 003171-

5269111. y.m.van_der_linden@lumc.nl

- Maastricht UMC (Maastricht), (<http://www.azm.nl/zorgcentra/zorgcentra/ZorgInLaatsteLevensfase/>), chair Dr. M.H.J. van den Beuken-van Everdingen, Postbus 5800 6202AZ Maastricht, tel. 003143 3876543 contact.a.courtens@lumc.nl

Other palliative care research centres:

- Lindeboom Instituut (<http://www.lindeboominstituut.nl/sitemanager.asp?pid=105>) Postbus 178, 3900 AD Veenendaal.
- University of Humanistic Studies (Utrecht) (<http://www.uvh.nl/>) prof dr C.J.W. Leget, Chair in ethical and spiritual questions in palliative care. Kromme Nieuwegracht 29, 3512 HD Utrecht, 0031-30-2390155.

Palliative care collaboration:

- In 2011, a Core Group for Palliative Care was formed. The Core Group for Palliative Care produced a "white paper" (2011) in which a national palliative care policy (2010-2020) was described. The Core Group for Palliative Care is a collaboration between Agora National Centre for Palliative Care, the Association of Independent High-Care Hospices, IKNL, Centres of Excellence for Palliative Care of the NFU, PalHag expert group of the NHG, Palliatief (the professional association of caregivers in palliative care), Foundation Fibula (platform for palliative care networks), VPTZ (Volunteers for Palliative Terminal Care) and V&VN Palliative Care (Nurses and Carers of the Netherlands in Palliative Care).
- Development of the structure of palliative care is also supported by the Ministry of Health, Wellbeing and Sports (VWS).
- Agora National Centre for Palliative Care supports the EAPC Taskforces on Spiritual Care and Physiotherapy. The Chair of the EAPC Taskforce on Spiritual Care is also on the EAPC board. The Netherlands is involved in the EAPC Taskforce on Social Work. There are several universities participating in international research.
- World initiative: De Internationale Dag van de Palliatieve Zorg (IDPZ) organized initiatives on World Hospice and Palliative Care Day (coordinated by Agora) until 2010. There are many other activities on this day all over the country, mostly organized by the networks of palliative care.
- Agora has brought together a variety of organisations in the coalition "Van betekenis tot het einde" (Meaningful till the end). This coalition focuses on public awareness of end of life issues; they wish to promote an attitude in society in which there will be room for aging, frailty, death and dying. Agora has contact with Dying Matters in the UK, and this provides a good example of how a broad public awareness campaign can successfully work.

Worldwide palliative care alliance level of development:

4B (Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision).

There are now 66 palliative care network organisations across the country; each one of them has one or more palliative care consultation service and unit. Four university palliative care expertise centres have been established and work together as centres of excellence

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

The Dutch government considers palliative care as generalist care instead of specialist care; therefore education is not recognized. However, there are initiatives developed by training institutes to provide education in palliative care. For example, there have been several initiatives to develop postgraduate training in palliative care, mainly for doctors and nurses but also for spiritual caregivers and social workers.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: There are special palliative care courses and programs for all medical students in their third and final year at several universities. The specialties of anaesthesiology, otorhinolaryngology and medical oncology all have special training programs in palliative care.
- Nursing: Palliative care education is integrated into nurse training at several institutions.
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: Palliative medicine is not considered as a separate discipline or specialization in the Netherlands. Nevertheless, several postgraduate specialization programmes have been developed by branch organizations of the palliative care networks (NAPC/NHG and V&VN PZ). There are special postgraduate training courses for GP's, nursing home physicians and medical specialists; there is also a continuing education program for doctors working in palliative care (available since 2012). As of 2013, approximately 200 GP's and nursing home specialists and 175 medical specialists had attended these courses (most of them were working in palliative care).
- Nursing: There is currently no specialization in palliative medicine for nurses. However, there are special postgraduate training programs for nurses in Utrecht and Rotterdam and there is a continuing education program for nurses working in palliative care (available since 2012); furthermore, the association of hospices has developed a "blended learning" educational program for nurses experienced in palliative care.
- Social work: There are different forms of continuous training programs in palliative care for social workers.
- Other professions: There are a number of different forms of continuous training programs in palliative care for other healthcare professionals (psychologists, chaplains, physiotherapists). A multidisciplinary course on medical ethics is also available.

Translation of palliative care documents or other materials:

- The nurses association has translated the EAPC guidelines "A Guide for the Development of Palliative Nurse Education in Europe" and used these guidelines for their "Quality chart for the development of palliative care in nurse education" (V&VN PV, 2008).
- The White Paper on dementia has been translated by Jenny van der Steen (EMGO, VUmc, Amsterdam).

Initiatives to develop healthcare professional leadership in palliative care:

- Postgraduate advanced course in palliative care (Nijmegen).
- Course on palliative care for medical specialists.
- Course on palliative care for GP's and nursing home physicians.
- The development of Palliatief, a multi-professional organisation for professionals in palliative care.
- Agora research initiatives.
- An annual Dutch – Belgian research congress.
- An annual palliative care congress for professionals in palliative care.
- Several educational initiatives at large hospices connected to academic centers (Leerhuizen Palliative Zorg, Laurens Cadenza, hospice Kuria, academic hospice Demeter).

Officially recognized medical certification:

- Currently, there is no formal specialization for physicians or nurses in Palliative Medicine in the Netherlands, although a number of organizations are developing specialization programs. There are many other different forms of continuing training programs for palliative care professionals (nurses, physicians, social workers, psychologists, chaplains, and physiotherapists): (<http://www.palliatiefconsult.nl/index.php?iPageId=5>) (<http://www.agora.nl/Themas/Scholing/tabid/4105/Default.aspx>)
- See also: consultation in palliative care (http://www.iknl.nl/page.php?id=3190&nav_id=84).

Capacity of palliative care workforce training in Universities and Medical Schools:

- The Netherlands has 28 medical schools (<http://www.stz-ziekenhuizen.nl/english.html>); it is not known how many possess palliative medicine as a mandatory or optional component.
- The Netherlands has seven full Professors of Palliative Medicine: The professors are:
 - Prof. Dr. Kris Vissers (UMC St. Radboud): Professor of palliative care.
 - Prof. Dr. Karin van der Rijt (Erasmus MC): Professor in palliative oncological care.
 - Prof. Dr. Carlo Leget (UvH): Professor in ethical aspects of palliative care and spiritual questions in relation to palliative care in hospices
 - Prof. Dr. Bregje Onwuteaka-Philipsen (VUmc): Professor in end-of-life research
 - Prof. Dr. Anneke Francke (VUmc): Professor of nursing and care at the end-of-life.
 - Prof. Dr. Luc Deliens (VUmc): Professor in public health and palliative care.
 - Prof Dr. Wouter Zuurmond (VUmc): Professor in pain relief and palliative care.
- In addition, Dr. Anne Mei Thé (UvA) is a Professor of care and dementia (with a Lectureship in palliative care, ethics and communication).
- In 2013, Dr. Agnes van der Heide (Erasmus MC), will become a Professor in end-of-life decision making.
- The Netherlands also has two associate professors in palliative care.

There has been improvement in Government policy, an increase in palliative care educational and training opportunities in local, regional and national programmes and an amelioration of national collaboration between all relevant organisations

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

All essential medications are available at all levels of health care.

Developments/opportunities/barriers relating to the accessibility of essential medications:

All essential medications are accessible at all levels of health care.

Developments/opportunities/barriers relating to the affordability of essential medications:

All essential medications are affordable as they are provided by the health care insurance law; patients do not have to pay when opioids are prescribed by a general practitioner or medical specialist.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There are no regulations that may restrict physician or patient access to pain relief.

Initiatives to promote attitudinal change in relation to 'opiophobia':

- The Comprehensive Cancer Centres have reviewed palliative care guidelines in relation to 'opiophobia'.
- A national consensus guideline has been published and implemented that attempts to persuade the patient to take the prescribed medications (including opioids). Special training courses have been implemented for healthcare providers to communicate more effectively on this subject with both patients and their families.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

Any opioid medication is accessible for all people in the Netherlands without restriction.

Initiatives that consider access to essential medication as a legal and human right:

No such initiatives have been undertaken as they are not needed in the Netherlands.

All essential medications are affordable as they are provided by the health care insurance law; patients do not have to pay when opioids are prescribed by a general practitioner or medical specialist

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- A special palliative care program (Platform Palliatieve Zorg) was initiated by the Ministry of Health. This three-year project involved a large amount of projects analysing the different ways in which palliative care is performed in different settings and by different organisations. Several important reports resulted from this platform; these reports are the basis of the further institutionalisation and organisation of palliative care at the national level. This platform ended in 2010 but in 2012 the Ministry of Health authorized a follow-up to the initiative detailing how palliative care should be organized, supported and implemented.
- The Dutch Federation of Academic Centres (NFU) started a program describing and organising palliative care in academic expertise centres and in relation to other hospitals and primary care support teams (academic tasks relating to patient care, research and education).
- On a national level, Agora National Centre for Palliative Care, the Comprehensive Cancer Centers, the Centres of Excellence and VPTZ (association of volunteers in palliative care), the association of hospices, the association of palliative care networks (Fibula) and the Dutch College of General Practitioners (NHG) produced a "white paper" (2011) in which a national palliative care policy (2010- 2020) is described.

The impact of these policy changes and ways in which they have been important:

- The different reports of the platform of palliative care have been submitted to the Ministry of Health and are due to be implemented by the individual organisations active in the field of palliative care.
- A specific payment system has been introduced for hospitals, so that multi-disciplinary teams can be supported financially.

Development of a national palliative care consensus:

The Comprehensive Cancer Centers have reviewed the Dutch guidelines for palliative care and new guidelines have been developed.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

The "Blijham" committee has proposed a new model for the support structure relating to palliative care in the Netherlands (2011).

Development of an advocacy framework for integrating palliative care into the health care system:

The Core Group of Palliative Care is committed to achieving 24 hour/7 day palliative care provision.

Strategies to improve political awareness and government recognition of palliative care:

The press release of a White paper of the Core Group for Palliative Care in the Dutch Parliament was followed by parliamentary questions to the governing political parties.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

- Financing system for the hospitals.
- Prolongation of the grant financing of palliative care network coordinators.
- Financial support for the Comprehensive Cancer Centers.
- Financial support of Agora.
- Financial support of VPTZ (national organisation of volunteers).
- Financial support for a paediatric palliative care program.
- A new grant program for the national research society (ZonMw).

Involvement with the European Union in relation to hospice and palliative care initiatives:

VU Medical Center and Erasmus MC participated in the EU FP7 programmes PRISMA and OPCARE9.

Development of initiatives framing palliative care as a 'human right':

There is no information available at this time.

General legislation relating to palliative care:

There is general legislation that states every person in the Netherlands has the right to receive adequate healthcare (this is required to receive basic health insurance).

Published national documents relating to palliative care standards and norms:

- Printed palliative care standards: Palliatieve zorg: Richtlijnen voor de praktijk. Dhr. Dr. A. de Graeff; Drs. J.M.P. van Bommel; R.H.P.D. van Deijck; dhr. R. Krol; mw. Drs. W.H. Oldenmenger; dhr. Dr. E.J. Vollaard (first edition 2005; latest edition 2010).
- Online palliative care standards: www.pallialine.nl

National Plan or Strategy of Palliative Care:

- The Core Group for Palliative Care campaigns for a National Program on Palliative Care based on the aims of the 'White Paper 2010-2020' to improve palliative care in the Netherlands.
- There is a need to change the support structure of palliative care in the Netherlands. Several organisations are attempting to design a new support structure which has to be implemented by 2013. Participants include: the Ministry of Health, Agora National Centre for Palliative Care, Fibula Platform for palliative care networks, Centres of Excellence for Palliative Care of the NfU (eight universities) and IKNL.

National Cancer Control Strategy:

There is a National Cancer Programme financed by the Dutch government. See IKNL (www.IKNL.nl) for specific information.

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy but it does not contain an explicit reference to palliative care provision (http://www.soaaids-professionals.nl/faq/faq_beleid.) In English (<http://www.soaaids.nl/english>).

National Primary Health Care Strategy:

There is a National Primary Health Care Strategy but it is not known if it contains an explicit reference to palliative care provision.

Designated policy maker for the delivery of palliative care services:

There is a designated policy maker for the delivery of palliative care services at the Ministry of Health, Welfare and Sport (VWS). The Ministry finances part of the support structure of palliative care.

Department of Health specific responsibility for the delivery of palliative care services:

The Department of Health has specific responsibility for the delivery of palliative care services.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There are systems of auditing, evaluation or quality assurance that monitor the standard of palliative care.

Opioid legislation/Pain guidelines:

- Opioid legislation: <http://maxius.nl/opiumwet>
- Pain guidelines: www.oncoline.nl; www.knmg.nl; <http://www.artsennet.nl/Richtlijnen/Richtlijn43468/Pijn-3.htm>

Funding of palliative care services:

- Palliative care consultation is funded by the Government.
- There may be partial payment required for palliative care provided in hospices (although this is mostly reimbursed by health insurance).
- There may be partial payment required for palliative care medications (although this is mostly reimbursed by health insurance – it depends on the type of medication).

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

- There is more public awareness about end-of-life care.
- There has been an increase in the number of palliative care volunteers (in total there are now in excess of 10,000 volunteers).
- There has been a series of publications/columns in daily newspapers (NRC) and on television.
- There has been an increase in the number of publication of books about bereavement.

Major public discussion, debate or controversy about hospice and palliative care:

There has been debate relating to the withdrawal of treatment at the end of life care initiated by The Royal Dutch Medical Association (KNMG): Symposium (2012) "Never give up? Ongoing treatment in the last phase of life".

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

- Every year there is participation in World Hospice and Palliative Care Day.
- The National Congress on Palliative Care.
- A multitude of lectures by palliative care experts.
- Participation in the coalition "Meaningful till the end".

Hospice or palliative care 'success' stories:

- Development of collaborating university centres of palliative care.
- Development of a national research programme.
- Transformation from NPTN to Palliatief.
- Presentation of National Guidelines for Symptom Management.
- White paper 2010-2020 and collaboration on a national level in the Core Group for Palliative Care.

Initiatives seeking the legalisation of euthanasia or assisted dying:

- Euthanasia and assisted suicide are legalised on the basis that certain criteria of due care are met.
(<http://knmg.artsennet.nl/Publicaties/KNMGpublicatie-levenseinde/Position-paper-The-role-of-the-physician-in-the-voluntary-termination-of-life-2011.htm>).

There has been debate relating to the withdrawal of treatment at the end of life care initiated by The Royal Dutch Medical Association (KNMG): Symposium (2012) "Never give up? Ongoing treatment in the last phase of life".

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

The development of palliative care in The Netherlands will be supported by different professional organisations; university expertise centers, IKNL, Agora, Fibula, NFU etc.. According to Dutch philosophy, palliative care is the responsibility of all healthcare professionals without the need for the development of a domain of medical specialisation. Discussion about this point of view will continue in the future as part of an emancipatory step-by-step approach.

Most significant issues facing hospice and palliative care in the next three years:

- Financial issues; different indications and measures of palliative care are pending that involve risk for the future of palliative care (hospices in particular).
- Decisions about the total number of hospice beds that are needed in the Netherlands as a whole and local/regional areas specifically.

Implications for palliative care relating to the current economic crisis:

- Reimbursement of all medications.
- The availability of sufficient workforce capacity to enable patients to receive palliative care in a setting of their choice.

The development of palliative care in The Netherlands will be supported by different professional organisations; university expertise centers, IKNL, Agora, Fibula, NFU etc..

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 5 |
| Hospital palliative care support team | 0 |
| Home palliative care support team | 1 |
| Mixed palliative care support team | 38 |
| Palliative care units in tertiary hospitals | 4 (31) |
| Palliative care units in non-tertiary hospitals | 13 (64) |
| Inpatient hospice | 0 |
| Day hospice/day care centre | 5 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- National Palliative Care Registry, www.pallreg.no.
- National survey of palliative care services performed by the National Directorate of Health in 2010.

Additional comments:

- The number of volunteers is based on reports from the services.
- Volunteers have not been reported in the national registry until now, but will be included in the new registry commencing 2012.
- The home care service is in Fransiscushjelpen in the capital (Oslo).
- The majority of mixed palliative care support teams have their main function within the hospitals where they are based, but all of them also serve the surrounding communities/primary care.
- Palliative care services are either integrated into hospitals or into nursing homes (in the community).
- The five day care services have a total of 84 places per week. Two of the services only provide day care; the other three have a day care centre as part of a comprehensive palliative care service with a mixed palliative care support team, in-patient unit and out-patient clinic.

Palliative care services for children:

There are no special services for children, but most of the mixed care teams also serve children's wards and children at home.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|-----------|--|
| 1977 | The first service for seriously ill and dying patients is established in Oslo: Fransiscushjelpen, a non-profit organisation providing home care. |
| 1994 | The first academic palliative care unit opens in Trondheim: the Palliative Medicine Unit (PMU) at St Olav's Hospital. |
| 1995 | There is a public hearing on the 'Treatment and Care of the Incurably Ill and Dying'. |
| 1996-1999 | A governmental committee is established and a report published giving professional recommendations concerning the development and organisation of palliative care; they become the main guidelines for the special needs of palliative care patients (including the relief of pain). |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

The most significant changes in Norway since 2006 are the recognition of the importance of the work in palliative care that is performed in nursing homes, with each patient in their own home, by the community and by the relatives. There has been a change of focus and more goal-oriented work since 2006. Some new hospices in nursing homes have been established. New palliative care units in hospitals have also been established, and the link and cooperation between hospitals and nursing homes and communities has improved.

Overall progress in hospice and palliative care:

Overall progress in hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

Hospitals: Whilst there is more exchange of knowledge and cooperation between hospitals and nursing homes, residential homes for the elderly and other community settings, there is less time for dying people, and patients are discharged very fast. There is also more aggressive treatment- sometimes resulting in suffering. Overall, palliative care provision in nursing homes, residential homes for the elderly and other community settings has improved.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

All the good work from the hospice movement has had a great effect on the understanding of the need for palliative care for all types of patients. From 2005, a palliative care programme was developed that extended from the hospice to the hospital, and then into some nursing homes. In Oslo, there are approximately 50 nursing homes; from 2009, a palliative care programme commenced involving all the nursing homes in that area (in cooperation with local hospitals).

Perceived barriers to the development of hospice and palliative care:

- There are not enough well-educated healthcare professionals.
- The lack of a will to spend enough money.
- Lack of understanding from politicians and leaders in general.

Perceived opportunities for the development of hospice and palliative care:

- The focus on this issue has increased.
- Politicians seem more willing to listen.

Other issues relevant to the development of hospice and palliative care:

There is no information available at this time.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- There is a National Association of Palliative Care – the Norwegian Association for Palliative Medicine (*Norsk forening for palliativ medisin* (NFPM)), which commenced in 2000 and has a website (www.palliativmed.org). NFPM is representative of the whole country but is predominantly an association for physicians (part of the Norwegian Medical Association).
- There is a second National Association of Palliative Care – the Norwegian Association for Palliative Care (*Norsk Palliativ Forening* (NPF)). NPF commenced in 2000 and has a website (www.palliativ.org); it is representative of the whole country and is a multi-professional association.
- There are two more National Associations: *JA til lindrende enhet og omsorg for barn* (YES to ensuring pain relief in children) which commenced in 2009, promoting palliative care for children (www.palliativbarn.no) and *Hospice Forum Norge* (Hospice Forum Norway) which commenced in 2009 to promote free-standing hospices (www.hospiceforum.no).

Directory or catalogue of palliative care services:

There is an online directory of palliative care services (www.pallreg.no) which commenced in September 2007 and is continuously updated (last updated October 2011).

Congresses, scientific meetings or scientific journals in palliative care:

- There are National Palliative Care Conferences – Landskonferanser om utfordringer ved livets slutt (Conference on challenges at the end of life). In addition, there are several local and regional meetings every year. The National Conferences are held every second year (the next conference is in 2012), a total of 550 people attended the last conference in 2010.
- There is a scientific journal of palliative care: *Omsorg* (Nordic Journal for Palliative Care) is published four times per year but unfortunately is not indexed in any of the major scientific databases.
- There have been 176 publications relating to the development of palliative care in Norway.

Palliative care research capacity:

- There is a palliative care research center: European Palliative Care Research Centre, Faculty of Medicine, Norwegian University of Science and Technology, Trondheim.
- There is a large group of researchers affiliated with the European Palliative Care Research Centre (www.ntnu.edu/prc/people; www.helse-bergen.no/palliasjon; dagny.haugen@helse-bergen.no; www.palliasjon.no; nina.aass@ulleval.no; <http://www.unn.no/category10326.html>; tone.nordoy@unn.no).
- In addition, there is palliative care research taking place at each of the other three Regional Centres of Excellence for Palliative Care in Norway.

Some new hospices in nursing homes have been established. New palliative care units in hospitals have also been established, and the link and cooperation between hospitals and nursing homes and communities has improved

Palliative care collaboration:

- There is an association working for palliative care in Estonia, www.estlandsforeningen.no. This association has links to a palliative care institution.
- The palliative care services at the Norwegian University of Science and Technology have palliative medicine collaboration with the faculty of Medicine in Martin, Slovakia.
- There is significant research collaboration with European and international groups through the European Palliative Care Research Centre. The Norwegian Association for Palliative Medicine runs the Nordic Specialist Course in Palliative Medicine together with the associations for palliative medicine in the other Nordic countries (Denmark, Sweden, Finland, Iceland) (www.nscpm.org). There is collaboration on the Nordic journal Omsorg and the Nordic Textbook of Palliative Care, edited by Professor Stein Kaasa.
- The Norwegian Cancer Society was important in pioneering palliative care in Norway. Fransiscushjelpen, the municipal palliative care home care organisation in Oslo, was also an important pioneer. The two palliative care organisations, the NFPM and the NPF, have also been active in the development of palliative care in Norway.
- World Hospice and Palliative Care Day initiatives are held by Hospice Lovisenberg, Oslo and Hospiceforum Norge; one of the National Associations arranged a seminar on World Hospice and Palliative Care Day (2011).

Worldwide palliative care alliance level of development:

4b (Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

There is no information available at this time.

Specific developments in under-graduate palliative care education initiatives:

There is no information available at this time.

Specific developments in post-graduate palliative care education initiatives:

There is no information available at this time.

Translation of palliative care documents or other materials:

There is no information available at this time.

Initiatives to develop healthcare professional leadership in palliative care:

There is no information available at this time.

Officially recognized medical certification:

- There is accreditation of Palliative Medicine as a Sub-specialty in Norway.
- Palliative Medicine can be a Sub-specialty of any clinical specialty.
- The candidate needs to undertake two years full-time clinical work in palliative care and complete a two-year theoretical training course (Nordic Specialist Course in Palliative Medicine, 180 hours) to be approved in the formal competence field of Palliative Medicine. Clinical training must take place in an approved service. At least one year of training must be in a hospital inpatient unit. The second year can be within a mixed palliative care support team or in a palliative care unit in a nursing home. The candidate must have a tutor and two hours palliative care education per week in addition to the course.
- Palliative Medicine became a Sub-specialty in 2011. It is a temporary regulation to be evaluated in 2014, but it is hoped and expected that it will become permanent. The Norwegian Directorate of Health certifies the accreditation process.
- To date, the number of people achieving Palliative Medicine as a Sub-specialty is 17, but many more are expected in 2012.

Capacity of palliative care workforce training in Universities and Medical Schools:

- Norway has four main universities and each of them has a medical school.
- Palliative care is mandatory in two of these schools and optional in all four.
- There are two full Professors of Palliative Medicine (one full-time, one part-time).
- There are two other Professors of Palliative Medicine (Two part-time (20%) positions for full Professors).

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

The availability of essential medications is very good.

Developments/opportunities/barriers relating to the accessibility of essential medications:

The accessibility of essential medications is very good.

Developments/opportunities/barriers relating to the affordability of essential medications:

The affordability of essential medications is very good.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

There is no information available at this time.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

There has been increased recognition of the importance of palliative care that is performed in nursing homes, with each patient in their own home, by the community and by family and relatives

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

There is no information available at this time.

The impact of these policy changes and ways in which they have been important:

There is no information available at this time.

Development of a national palliative care consensus:

In 2009 the Helsedirektoratet (Health Directorate) published standards of palliative care. These guidelines are for all professionals who are working with terminally-ill patients. The guidelines are revised continuously.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

There is no information available at this time.

Development of an advocacy framework for integrating palliative care into the health care system:

There is no information available at this time.

Strategies to improve political awareness and government recognition of palliative care:

There is no information available at this time.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

There is no information available at this time.

Involvement with the European Union in relation to hospice and palliative care initiatives:

There has been cooperation between hospitals in Oslo and hospitals in Tallinn and Narva, Estonia, where new hospices have been established. Palliative care teaching and coaching have been provided by different institutions in Norway.

Development of initiatives framing palliative care as a 'human right':

There is no information available at this time.

General legislation relating to palliative care:

There is no specific law governing the provision of palliative care services, but as palliative care is integrated into mainstream health care, the laws governing the provision of health care also cover palliative care.

Published national documents relating to palliative care standards and norms:

- There are printed National Palliative Care Standards - *Nasjonalt handlingsprogram med retningslinjer for palliasjon i kreftomsorgen* (National Program for Palliative Care). The First Edition was published in December 2007, and updated in April 2010. The document is based on the Norwegian Standard for Palliative Care, published by the Norwegian Association for Palliative Medicine in 2004.
- There are also National Palliative Care Standards online (www.helsebiblioteket.no/Retningslinjer/Palliasjon) which first went online in 2010 (as a revised version of the printed document).

National Plan or Strategy of Palliative Care:

There is a National Plan/Strategy of Palliative Care - *Nasjonalt handlingsprogram med retningslinjer for palliasjon i kreftomsorgen* (National Palliative Care Program, updated 2010). This document includes standards and norms, clinical guidelines, and a national plan and strategy.

National Cancer Control Strategy:

The National Cancer Control Strategy *Nasjonal kreftstrategi* (2006-2011) (Norwegian National Cancer Strategy) was issued by the Minister of Health and contains an explicit reference to palliative care provision.

National HIV/AIDS Strategy:

The National HIV/AIDS Strategy *Aksept og mestring. Nasjonal hivstrategi* (2009-2014) (National Strategy for HIV 2009-2014) does not contain an explicit reference to palliative care provision.

National Primary Health Care Strategy:

The National Primary Health Care Strategy *Samhandlingsreformen* (Coordination reform).

Nasjonalt helse-og omsorgsplan (National Health Care Plan) (2011-2015) contains an explicit reference to palliative care provision.

Designated policy maker for the delivery of palliative care services:

There is no designated policy maker for the delivery of palliative care services.

Department of Health specific responsibility for the delivery of palliative care services:

There is specific responsibility in the Department of Health for the delivery of palliative care services - palliative care provision is included in the National Health Care Strategy and Cancer Strategy.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

The reimbursement system for palliative care in hospitals is linked to special requirements for the services. The four Regional Centres of Excellence for Palliative Care have a role in auditing the services in their respective regions. The formally competent field of Palliative Medicine (Sub-specialty) will be linked to an audit system securing the necessary quality at departments offering training positions in palliative medicine.

Opioid legislation/Pain guidelines:

- A special prescription must be signed. Any fully qualified physician may prescribe strong opioids.
- The physician must pay a minor fee for the prescription forms.
- Strong opioids are fully available upon prescription, both inside and outside of hospitals.
- There are pain guidelines (http://www.legeforeningen.no/asset/42585/1/42585_1.pdf) *Retningslinjer for smertelindring* (Guidelines for Pain Relief) (Norwegian Medical Association, NMA, 2009). The National Program for Palliative Care also includes pain guidelines which have been harmonized with the NMA document. They will be revised in 2012 to comply with the new EAPC/EPCRC Opioid Guidelines.
- Pain guidelines are also available online (<http://www.legeforeningen.no/id/154988.0>) *Retningslinjer for smertelindring* (Guidelines for pain relief) (Norwegian Medical Association, NMA, 2009).

Funding of palliative care services:

- Outpatients pay a regular fee for non-specialist and specialist consultations. When a fixed yearly amount has been reached, further consultations are free. Consultations for children are free.
- All inpatient services are free.
- All medications for symptom relief in advanced illness are free, independent of diagnosis. There is an extensive list of opioids approved for this regulation.
- The government has funds for community palliative care development that municipalities may apply for.

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:
There is no information available at this time.

Major public discussion, debate or controversy about hospice and palliative care:
There is no information available at this time.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:
There is no information available at this time.

Hospice or palliative care ‘success’ stories:
There is no information available at this time.

Initiatives seeking the legalisation of euthanasia or assisted dying:
There is no information available at this time.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:
There is no information available at this time.

Most significant issues facing hospice and palliative care in the next three years:
There is no information available at this time.

Implications for palliative care relating to the current economic crisis:
There is no information available at this time.

In 2009, standards of palliative care were published and there is a National Plan/Strategy of Palliative Care (2010). Palliative Medicine became a Sub-specialty in 2011 and there are now two full Professors of Palliative Medicine

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 87 |
| Hospital palliative care support team | 8 |
| Home palliative care support team | 321 |
| Mixed palliative care support team | 2 |
| Palliative care units in tertiary hospitals | 8 |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 137 (2232) |
| Day hospice/day care centre | 7 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- A. Ciałkowska-Rysz.
- A. Kotlińska-Lemieszek.
- Indirect data from National Health Fund.
- Ocena sytuacji w opiece paliatywnej w Polsce w 2011 roku (An appraisal of the situation of palliative care in Poland in 2011). A. Ciałkowska-Rysz, T. Dzierżanowski.
- Pediatria Domowa Opieka Paliatywna w Polsce 2010 (Paediatric Home Palliative Care in Poland) Raport XII. T. Dangel, M. Murawska, W. Marciniak, K. Dangel.

Additional comments:

- Hospital palliative care support teams exist in those hospitals where there is a palliative medicine outpatient or inpatient unit. They are not paid for by the National Health Fund. Physicians and nurses care for patients on other units if they are asked for assistance by the attending physician, e.g. internal units, etc. For this reason, their number is relatively low.
- The overall number of palliative care inpatient units in Poland in 2011 was 145. Eight of the units are linked to University hospitals and were therefore classified in this category.
- In Poland, there are inpatient units for patients with chronic diseases who require temporary social support; however, in Poland they are not included in the system of palliative care (but rather long-term care units, nursing homes, etc.).
- The individual number of beds in different types of institutions providing palliative care is unknown; an estimate is provided for the total number of beds.
- There are seven daycare centers linked to freestanding hospices. Their activities are not covered by National Health Funding (as of 2011); there are funded foundations which support individual hospices.

Palliative care services for children:

All hospices for adults admit children in need - there is no limitation. There are 48 paediatric home palliative care support teams.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|------------------|---|
| 1981-1990 | 17 hospices are established in Poland through the voluntary hospice movement. |
| 1994-2002 | The Ministry of Health and other sponsors offer financial support for the postgraduate training of doctors and nurses; |
| 1998 | The Program for Palliative Care is introduced by the Ministry of Health; |
| 1999 | Palliative medicine is introduced as a medical specialty. |
| 2002 | Changes are made in Polish Pharmacopeia VI ed. 2002: an increase in the maximum dosages of morphine in cancer pain; the rise of single oral morphine dose to 100 mg (and 20 mg for single intravenous morphine dose); |
| 2003 | Postgraduate training is made possible through the support of private sponsors and pharmaceutical companies. |
| 2003 | The Internet Information Service of the National Consultant is established which provides all important up-to-date information and offers a place where opinions are exchanged with other staff and the general public; |
| 2003 | "Torun Declaration about euthanasia" – 180 participants of a Palliative – Hospice Conference sign up to protest against euthanasia. |
| 2004 | The Council of Europe Report on Palliative Care (2003) (Recommendation 24 of the Committee of Ministers to member states on the organisation of palliative care) is translated into Polish, published, and copies sent to Regional Consultants of palliative medicine to give to palliative/hospice units (although it does not play an essential role in the development of Polish palliative care); |
| 2005 | The National Program for Cancer Care (including palliative care development) is accepted by the Polish Parliament. |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- The Ministry of Health Order (2009) regarding guaranteed services in hospice and palliative care.
- Growth in the number of palliative care units
- Growth in the number of palliative care specialists
- Introduction of palliative care specialization for nurses
- There has been some growth in financial expenditure for palliative care but it is still inadequate – approximately 15% of home-based palliative care services are not reimbursed by the National Health Fund and it is not known how many cancer and non-cancer patients are unable to access specialist palliative care.

Overall progress in hospice and palliative care:

There has been minor progress in hospice and palliative care (but not enough to secure growing patient needs).

Development of hospice and palliative care in different health and social care settings:

- Hospitals: The number of inpatient units has grown. Hospital patients are consulted about admittance to inpatient units.
- Nursing homes: The residents of nursing homes have access to home-based palliative care.
- Residential homes for elderly: Theoretically, residents of residential homes have access to home-based palliative care (but the awareness of their needs is not adequate in those institutions)
- Other community settings: The number of home-based palliative care teams has grown, but there are still "blank spots" where there is a lack of palliative care units (mostly in the South-Eastern part of the country)

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

- HIV/AIDS patients had access to palliative care prior to 2006; now palliative care services are also provided for patients with heart failure, respiratory disorders, wounds and bedsores, and SLA.
- The exceptions in this area are patients with dementia and patients with strokes (neuro-muscular diseases, congenital diseases and other conditions), who are directed to nursing therapeutic centers and neurological rehabilitation centers.

Perceived barriers to the development of hospice and palliative care:

- Poor communication with representatives from the National Health Fund (the health care reimbursing organisation).
- Despite the fact that there have been significant expenditures in other areas of healthcare, there is insufficient financing of palliative care services: reimbursement of inpatient palliative care covers about 60% of total expenditure; and there is no reimbursement for approximately 15% of home care.
- As a result of insufficient financing, hospices experience financial difficulties and have to find alternative ways to overcome such difficulties for example, by establishing a "queuing system" for patients).
- Although some patients with non-oncological disease now receive palliative care, hospices may still not be eligible for reimbursement.
- There are too few inpatient palliative care units in comparison to the required need.

Perceived opportunities for the development of hospice and palliative care:

- A larger number of home-based palliative care teams (mainly in "blank spot" areas of Poland)
- Extension of palliative care services for non-cancer patients
- Improved collaboration with the Ministry of Health and the National Health Fund (palliative care should be more widely acknowledged by decision-making authorities - there is still insufficient lobbying activity)
- Improved accessibility to continuous medical education programs (there are many palliative care training programs for physicians and nurses)
- Established national guidelines and standards for palliative care (based on EAPC principles).

Other issues relevant to the development of hospice and palliative care:

- Promulgation about the legal role of hospice and palliative care in the national health care system.
- An effective procedure has been developed for the launch of new analgesics that are available in the European Union.
- Publication of a scientific journal on palliative medicine since 2009 (official PTMP edition).

There has been a growth in home care teams, palliative care units and specialists. Palliative care has been introduced as a specialization for nurses and some nursing homes have access to palliative care. Palliative care is provided for 'non-cancer' patients.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- The Polish Society of Palliative Medicine (Polskie Towarzystwo Medycyny Paliatywnej) was formed in 2002; the association has a website (www.medycynapaliatywna.org), and is representative of the whole country.
- The Polish Association for Palliative Care (Polskie Towarzystwo Opieki Paliatywnej) was formed in 1993; the association was initially active in only two regions of Poland, and is currently not representative of the whole country.
- Other relevant organisations include: Polish Society of Palliative Care Nursing; and Polish Hospices Forum (which coordinates the work of non-profit hospices).

Directory or catalogue of palliative care services:

There is a directory or catalogue of palliative care services in process.

Congresses, scientific meetings or scientific journals in palliative care:

- The Congress of Polish Association of Palliative Medicine is a national congress held every three years and attended by approximately 500 participants.
- The Conference of Palliative Medicine is held annually and attended by approximately 200-300 participants.
- The Conference of Palliative Medicine in Practice is held annually and attended by approximately 200-300 participants.
- Regional or local palliative care conferences are held annually at eight centres and attended by approximately 200-300 participants.
- The journal *Medycyna Paliatywna* (Palliative Medicine) is published four times per year.
- The journal *Advances in Palliative Medicine* is published four times per year (Index Copernicus (4.89), Ministry of Education (6 pts.) EMBASE).
- The journal *Medycyna Paliatywna w Praktyce* (Palliative Medicine in Practice) is published four times per year.

Palliative care research capacity:

There are 15 research centres where palliative care studies have been performed:

- Bydgoszcz - M. Krajnik (mkrajnik@poczta.onet.pl);
- Bydgoszcz - A. Stachowiak (a.stachowiak@domsueryder.org.pl);
- Gdansk - M. Lichodziejewska-Niemierko (lichotek@amg.gda.pl);
- Gliwice - A. Pakosz (pakosz@vp.pl);
- Katowice - J. Pyszkowska (pyszkat@pro.onet.pl);
- Katowice - M. Janecki (janeckimarcin@op.pl);
- Kraków - I. Bryniarska (inusia_bryniarska@yahoo.pl);
- Łódź - A. Ciałkowska-Rysz (olarysz@rmed.pl);
- Łódź - A. Mardofel (anna.mardofel@gmail.com);
- Poznań - A. Kotlinska-Lemiesze (alemieszek@ump.edu.pl);
- Poznań - W. Leppert (wojciechleppert@wp.pl);
- Poznań - M. Sopata (maciej.sopata@skpp.edu.pl);
- Szczecin - M. Sznabel-Lembas (msznabel@sci.pum.edu.pl);
- Warszawa - T. Dzierzanowski (praktyka@adiutus.pl);
- Warszawa - T. Dangel (dangel@hospicjum.waw.pl) (hospice for children);
- Wrocław - A. Orońska (aoronska@biskupin.wroc.pl);
- Wrocław - E. Mess (wp-2.2@am.wroc.pl).

Palliative care collaboration:

- Palliative care experts from different institutions have collaborated with the National Consultant in Palliative Care and the Polish Society of Palliative Medicine (on changes implemented by the Ministry of Health and National Health Fund relating to policy, programmes of education in palliative care, etc.).
- The hospices in Łódź (Dr Ciałkowska-Rysz) and Poznań have assisted with the development of postgraduate palliative care education for participants from Ukraine and Belarus.
- Łódź Hospice Association and Pracownia Medycyny Paliatywnej at Łódź Medical University cooperate with hospices or groups of people developing palliative care services in Ukraine, Belarus, Armenia, Lithuania, Croatia, and Kazakhstan.
- Participants from Ukraine have attended Wrocław Hospice for palliative care courses and clinical training.
- Sue Ryder House and Sue Ryder Association in Bydgoszcz cooperate with:
 - Sue Ryder Foundation in Warsaw.
 - Sue Ryder Foundation in United Kingdom.
 - other palliative care units situated in Sue Ryder Houses in Poland.
 - palliative care units in Republic of Macedonia.
- All hospices and palliative care organizations promote and celebrate World Hospice and Palliative Care Day.

Worldwide palliative care alliance level of development:

4B (Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision).

The Ministry of Health passed an Order in 2009 regarding guaranteed services in hospice and palliative care and the legal role of hospice and palliative care in the national health care system has been promoted

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- There have been continuous palliative care education and training initiatives since educational programs were defined by an Order from the Ministry of Health. Medical universities (and the units appointed to provide specialization programs for physicians) are eligible to provide post-graduate educational initiatives.
- Training initiatives for nurses are provided according to the program set by the Post-graduate Educational Center for Nurses.
- Sue Ryder House and Sue Ryder Association in Bydgoszcz founded a special project: the Polish School of Palliative Medicine which provides postgraduate education for doctors, nurses and physiotherapists.
(www.domsueryder.pl, www.psmmp.pl).

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Under-graduate palliative care education programs have been developed.
- Nursing: Under-graduate palliative care education programs have been developed.
- Social work: Social care is a separate domain that is within the remit of the Ministry of Social Care (social workers are educated separately).
- Other professions: There is a palliative care training program for psychologists provided by Polskie Towarzystwo Psychoonkologiczne (Polish Society of Psychooncology).

Specific developments in post-graduate palliative care education initiatives:

- Medicine: Since 2006, the number of centres eligible to provide postgraduate palliative care education courses has increased; training sessions are included in specialisation programs for oncologists, internal medicine specialists, and family doctors.
- Nursing: Palliative care is a nursing specialisation (two years duration); there is also a qualification course in palliative care (six months duration).
- Social work: No developments.
- Other professions: No developments.

Translation of palliative care documents or other materials:

- The EAPC "White Paper on Standards and Norms for Hospice and Palliative Care in Europe" has been translated.
- A few foreign handbooks have been translated and used in lectures.

Initiatives to develop healthcare professional leadership in palliative care:

Initiatives to develop healthcare professional leadership in palliative care are provided by the Medical Universities.

Officially recognized medical certification:

- Palliative medicine as a specialisation for physicians is subject to the same regulations as other medical specialties.
- There has been a specialty in palliative medicine in Poland since 1999 (dependent on the Ministry of Health). It consists of five educational courses (introduction, pain and symptom control, psychological and social issues), six months training in a palliative care inpatient unit, six months training in either home-based palliative care or at a palliative medicine outpatient clinic, two weeks training in a Pain Clinic, four weeks training in an Oncology Department, and two weeks training in an Intensive Care Unit. To date, 276 professionals have become specialists in palliative medicine in Poland.
- However, the system is going to be changed 'in the near future' - there will be two possibilities: accreditation following training (as described above), or; directly after graduation - five years of specialization, which will be divided into two years of general education (for example, in internal medicine), and then three years of specialization in Palliative Medicine.
- There are postgraduate courses in palliative care that focus specifically on home-based care. They consist of 40 hours of seminars and workshops and four weeks of clinical training in a palliative care inpatient unit and home-based care team. To date, approximately 1,200 physicians and 2,100 nurses have completed these courses.

Capacity of palliative care workforce training in Universities and Medical Schools:

- In Poland, there are 14 medical schools, nine of which have palliative care as an obligatory component (one has palliative care as an optional component). Courses that are mandatory also offer the possibility of attending further optional courses on pain management, end-of-life care etc.
- There are four recognized full Professors of Palliative Medicine in Poland - although it is possible that the total number may be as many as eight. This is because in Poland, there are three definitions of the title 'Professor' - dr habilitowany - the lowest degree, supraordinary and ordinary professor (the highest) - it is estimated that there are two dr hab. and six professors. In Poland, the degree does not have a direct relation to a position at a University (Head of Chair of Palliative Medicine). Professors may not have a University Chair or be the leaders of a University Department.
- There are a further two Emeritus Professors who work at Universities and teach students and postgraduates about palliative care; there is also one "full professor non-medical".

An effective procedure has been developed for the launch of new opioid analgesics that are available in the European Union. A scientific journal on palliative medicine has been published since 2009

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- Morphine – vials, tablets, controlled release tablets are available.
- Oxycodone – vials, tablets, controlled release tablets are available.
- Buprenorphine – patches, tablets, vials are available.
- Fentanyl – patches, transmucosal formulations are available.
- Essential medications that receive reimbursement status: Oxycodone; Fentanyl (Transmucosal preparations).

Developments/opportunities/barriers relating to the accessibility of essential medications:

As above.

Developments/opportunities/barriers relating to the affordability of essential medications:

As above.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

There have been campaigns undertaken by non-governmental organizations relating to the "fight against pain".

Initiatives that examine access to opioid medication for economically disadvantaged persons:

Opioid medications are free of charge or low basic price (mostly for cancer patients)

Initiatives that consider access to essential medication as a legal and human right:

Such initiatives are not necessary (see above).

The National Palliative Medicine Council was established by the Ministry of Health in September 2011. It consists of ten leaders in the field of hospice/palliative care in Poland. The goals of the Council include developing norms and amendments to legislation related to palliative care

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

Ministry of Health Act (2009) on guaranteed services in palliative and hospice care.

The impact of these policy changes and ways in which they have been important:

The Act has defined the range of free guaranteed services, the standards of equipment of palliative care units, staff norms and the minimum qualification levels for physicians and nurses.

Development of a national palliative care consensus:

The standards for inpatient, home-based and outpatient care have been defined in the Act mentioned above.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

In 2011, the Ministry of Health established the National Council for Palliative and Hospice Care, whose aim is to develop a national strategy of palliative care.

Development of an advocacy framework for integrating palliative care into the health care system:

Palliative care is integrated within the Polish health care system (but only weakly integrated).

Strategies to improve political awareness and government recognition of palliative care:

There have been numerous meetings, conferences, and publications to improve political awareness and government recognition of palliative care.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

- In 2008, based upon the Ministry of Health Order, public expenditure on palliative care increased by approximately 30% (in 2011, by approximately 4-8%).
- Each citizen is allowed to donate 1% of their annual tax on designated non-profit organizations (including palliative care-related ones).

Involvement with the European Union in relation to hospice and palliative care initiatives:

Poland has participated in a number of conferences organized by the European Union.

Development of initiatives framing palliative care as a 'human right':

Palliative care was already treated as a 'human right' prior to 2006.

General legislation relating to palliative care:

The provision of palliative care services is governed by: The Act of August 24th, 2007 amending the Act on healthcare services financed from public funds; Regulation of Ministry of Health (29th August 2009) on medical services guaranteed in palliative and hospice care.

Published national documents relating to palliative care standards and norms:

Regulation of Ministry of Health (24th January 2011) amending regulation on medical services guaranteed in palliative and hospice care (First edition 2009, latest edition 2011).

National Plan or Strategy of Palliative Care:

The National Palliative Medicine Council was established by the Ministry of Health in September 2011. It consists of ten leaders in the field of hospice/palliative care in Poland. The goals of the Council include developing norms and amendments to legislation related to palliative care.

National Cancer Control Strategy:

The National Program against Cancer Diseases (2006-2015) was implemented in 2005 (it includes palliative care).

National HIV/AIDS Strategy:

In Poland, people with HIV/AIDS receive treatment and are cared for primarily by specialists of infectious diseases. The work is coordinated and supervised by the National Center for AIDS, and the Ministry of Health (separate from palliative care), who developed a strategy for the management of this group of patients (National Program for Combating AIDS and HIV Prevention, 2005). They may be consulted by physicians in palliative care units (which are reimbursed by the National Health Fund).

National Primary Health Care Strategy:

The National Primary Health Care Strategy contains a reference to palliative care.

Designated policy maker for the delivery of palliative care services:

- A National Consultant in Palliative Medicine has been designated every five years by the Minister of Health since 1999 (for a maximum term of 10 years).
- The National Palliative Medicine Council (established in September 2011).

Department of Health specific responsibility for the delivery of palliative care services:

- The Department of Health has to guarantee the provision of palliative care in home-based care, outpatient clinics, inpatient units and hospices, although currently it does not have an obligation to guarantee financing palliative care support teams or daycare centres.
- The Department of Health is responsible for the specialization of physicians and nurses in palliative medicine.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

- The National Consultant in Palliative Medicine has responsibility for the whole system of palliative care in the country. They are responsible for each voivodeship (province - there are 16 voivodeships in Poland); the consultant may assume control for palliative care units in their region.
- The National Health Fund regularly assumes control of palliative care units if they possess appropriate means (specialized professionals, equipment etc.) and if they provide adequate care
- Some palliative care units have introduced ISO certification.

Opioid legislation/Pain guidelines:

- Opioid: Strong opioids (morphine, oxycodone, fentanyl, and methadone) and codeine have to be prescribed on a special prescription with a copy provided (the prescription used to be pink in colour but has now been replaced by a white form); there are still no changes to the process of obtaining a prescription which continues to be very complicated and time-consuming (due to this, a lot of doctors avoid the prescription of "strong" opioids). Each prescription has a number which has to be recorded on the patient's medical chart. This is partly related to the lack of a complete electronic system of prescribed drugs in Poland.
- However, each physician who has the right to practice (after one year of clinical training and an examination) can prescribe opioids (family doctors, oncologists, palliative medicine specialists etc.). DHC, tramadol and buprenorphine can be prescribed on 'regular' prescriptions and are also available without limitation at the patient's home (in required doses). The maximum dose which can be prescribed on one prescription depends on the type of formulation.

There are printed pain guidelines:

- J.Kujawska-Tenner, J.Łuczak, M.Okupny, A.Kotlińska, T.Dangel: Zwalczanie bólów nowotworowych (Cancer pain relief) Ministerstwo Zdrowia i Opieki Społecznej, Warszawa 1994.
- M.Hilgier, J.Jarosz. Leczenie bólu u chorych na nowotwór – standardy i wytyczne. *Terapia*, 2006;11, 35-41
- J.Dobrogowski, M.Krajnik, J.Jassem, J.Wordliczek. Stanowisko dotyczące postępowania przeciwbólowego u chorych Na nowotwory. Consensus statement with focus on cancer pain management. *Onkologia w praktyce klinicznej* 2009; 5, 2; 55-68.

Funding of palliative care services:

- There is no payment required for palliative care consultation or hospitalisation
- Partial payment may be required for palliative care medications: patients have to pay for some adjuvants, but opioids are free of charge (or at low basic price for patients with cancer and some other chronic pain syndromes).
- Payment for palliative care is "not disease-specific"; however, according to the National Health Fund (NHF), only patients with cancer, HIV, cardiomyopathies, respiratory impairments, sequelae of inflammatory diseases of the central nervous system, bedsores and SLA are eligible for palliative care (and are reimbursed by NHF). Other groups of patients, e.g. dementia, stroke etc. are not listed as being eligible for palliative care. They are included in the system of long-term care, and can be referred to neurological rehabilitation centres and nursing homes.

A National Consultant in Palliative Medicine has been designated every five years by the Minister of Health since 1999 (for a maximum term of 10 years)

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

There has been an increase in public awareness as a result of social campaigns in the media and also in schools.

Major public discussion, debate or controversy about hospice and palliative care:

There is no information available at this time.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

Initiatives that seek to broaden awareness and understanding of hospice and palliative care include national media campaigns (e.g. "Hospice is life too").

Hospice or palliative care 'success' stories:

- Access to the newest medications
- Basic legal regulations.
- High number of effective home care teams.

Initiatives seeking the legalisation of euthanasia or assisted dying:

Initiatives seeking the legalisation of euthanasia or assisted dying are not provided for nor planned in Poland.

References

Leppert W; Luczak J. March-April 2007. "A holistic approach to palliative care in Poland". *European Journal of Palliative Care*; 14 (2): 80-3.

Hess-Wiktor K. September-October 2009. "What does it mean to be a hospice volunteer in Poland?". *European Journal of Palliative Care*; 16 (5): 249-51.

Esther Schmidlin. March-April 2013. "Hospice and palliative care in Poland – current challenges and solutions". *European Journal of Palliative Care, Volume 20 Number 2*, p 92-94.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

Currently, home-based palliative care teams function well in Poland. However, further development of inpatient units is necessary as their overall base is too small. Hospital support teams are not reimbursed, so their number is also too low.

Most significant issues facing hospice and palliative care in the next three years:

- Palliative medicine is a specialisation that is subject to the same regulations as other medical specialties.
- The future depends on the amounts spent on health care services in the country. They are too small and should be increased. The combination of an ageing society and providing palliative care to non-oncological patients will require increased expenditure on palliative care services.
- The members of non-governmental organizations have a consultative voice and may provide an opinion on future legal acts.

Implications for palliative care relating to the current economic crisis:

The economic crisis has not had a noticeable impact to date. It is possible that some expensive medicines will become less accessible.

The members of non-governmental organizations have a consultative voice and may provide an opinion on future legal acts

Portugal¹

NATIONAL ASSOCIATION

Portuguese Association for Palliative Care

*Associação Portuguesa
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 2 |
| Hospital palliative care support team | 18 |
| Home palliative care support team | 10 |
| Mixed palliative care support team | 4 |
| Palliative care units in tertiary hospitals | 5 (70) |
| Palliative care units in non-tertiary hospitals | 17 (180) |
| Inpatient hospice | 0 |
| Day hospice/day care centre | 1 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

Personal estimates/estimates provided by experts.

Additional comments:

- Volunteers are not organized teams but groups with some education in palliative care.
- 14 of the beds included in palliative care units in non-tertiary hospitals are in a non-public hospital.

Palliative care services for children:

There are no specific palliative care services for children.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

June 6th 2006 Law 101/2006 establishing the National Network for Continuing Care (recognizing the right to palliative care).

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

There has been an increase in the number of post-graduate palliative care courses, and an increase in the number of palliative care services provided by the National Continuity Care Integrated Network.

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: the number of palliative care beds and hospital palliative care support teams have increased (but these teams are not providing care for acute patients)
- Nursing homes: There is no information available at this time.
- Residential homes for the elderly: There is no information available at this time.
- Other community settings: There is no information available at this time.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

There has been no expansion - the vast majority of patients receiving palliative care are cancer patients (approximately 95%).

Perceived barriers to the development of hospice and palliative care:

- Policy makers do not prioritize palliative care.
- Lack or absence of specialized education of health care professionals working in palliative care.
- Palliative care is not recognised as a medical speciality.

Perceived opportunities for the development of hospice and palliative care:

- The norm that places an obligation on hospitals to provide hospital palliative care support teams
- Development of specialities in medicine and nursing (in process)
- September 4th 2012 - Law 52/2012: Law on Palliative Care establishing the National Network for Palliative Care.

Other issues relevant to the development of hospice and palliative care:

The EAPC Congress in Lisbon (May 2011) increased the visibility of the National Association of Palliative Care.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

The Portuguese Association for Palliative Care (Associação Portuguesa de Cuidados Paliativos) was formed in 1995; the association has a website (www.apcp.com.pt) and is representative of the whole country.

Directory or catalogue of palliative care services:

There is a directory of palliative care services in preparation at this time.

Congresses, scientific meetings or scientific journals in palliative care:

There is a National Congress of Palliative Care, held biannually and attended by approximately 300 participants.

Palliative care research capacity:

Researchers include:

- Manuel Luís Capelas (manueluis.capelas@gmail.com);
- Filipa Tavares (phillipa.tav@gmail.com);
- Edna Gonçalves (ednagoncalves@gmail.com);
- Paula Sapeta (paula.sapeta@gmail.com).

Palliative care collaboration:

- The Lisbon Academic Center is a partnership between the Faculty of Medicine of the University of Lisbon, the Palliative Care Department of the "Hospital da Luz", S. Benito de Menni and the hospital palliative care support team of the North Lisbon Hospital Centre.
- The VI National and I Lusophone Congress in Palliative Care was held in October 2012 to celebrate World Hospice and Palliative Care Day.

Worldwide palliative care alliance level of development:

4a (Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision).

There has been an increase in the number of palliative care services provided by the National Continuity Care Integrated Network; the number of palliative care beds and hospital palliative care support teams have increased

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- There has been an increase in the number of basic courses and post-graduate courses in palliative care.
- The EAPC Congress in Lisbon (May 2011).

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Some medical faculties have integrated palliative care into their curricula; others offer this as an optional component.
- Nursing: Some schools of nursing have palliative care as an obligatory component in their curricula (and others as optional). However, the subject is not mandatory in many nursing courses so there are schools that don't have this subject available in their curricula.
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: The number of multidisciplinary post-graduate courses in palliative care has increased; some medical associations have promoted basic palliative care courses within their initiatives
- Nursing: As medicine
- Social work: The number of multidisciplinary post-graduate courses in palliative care has increased
- Other professions: The number of multidisciplinary post-graduate courses in palliative care has increased. Core courses in palliative care are offered for various professional fields.

Translation of palliative care documents or other materials:

A number of palliative care documents or other materials have been translated: IMPaCCT; Standards for Paediatric Palliative Care in Europe; Palliative Care for Infants, Children and Young People -The Facts.

Initiatives to develop healthcare professional leadership in palliative care:

There is no information available at this time.

Officially recognized medical certification:

- There is no officially recognized medical certification, although competence in palliative care is subject to approval by the professional organization of physicians (Ordem dos Médicos).
- There are several Master degree courses available for doctors and other professionals requiring certification of advance training in palliative care.

Capacity of palliative care workforce training in Universities and Medical Schools:

- Portugal has seven medical schools; an estimated two of them offer palliative care as an optional component (source: Minister of Science and Superior Education).
- Since 2012, there has been funding provided from a private foundation for a Chair in Palliative Medicine at the University of Lisbon (directed by Dr. Peter Lawton, a University Professor from Ottawa, Canada).
- There are professors of several other medical disciplines that promote the concept of palliative care within the University (University of Beira Interior and others.).

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

In general, essential medications are available.

Developments/opportunities/barriers relating to the accessibility of essential medications:

Accessibility to essential medications has improved since publication of the law which facilitates the prescription of opioids.

Developments/opportunities/barriers relating to the affordability of essential medications:

The price of essential medications has decreased since 2010.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

- The law which facilitates the prescription of opioids
- Electronic prescription has eliminated some mandatory bureaucracy.

Initiatives to promote attitudinal change in relation to 'opiophobia':

There have been several interviews on TV and in other forms of media in relation to 'opiophobia'; some conferences and basic courses in palliative care have also initiated discussions about this issue.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no opioid discrimination in Portugal against economically disadvantaged persons.

Initiatives that consider access to essential medication as a legal and human right:

The law which facilitates the prescription of opioids has improved access to pain relief (but for other symptoms there has been little progress).

There has been an increase in the number of undergraduate and postgraduate courses in palliative care. Some medical faculties and schools of nursing have integrated palliative care into their curricula

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- The National Continuity Integrated Care Network (2006) and the National Palliative Care Program (2010).
- September 4th 2012 - Law 52/2012: Law on Palliative Care establishing the National Network for Palliative Care.

The impact of these policy changes and ways in which they have been important:

The number of palliative care resources has increased but the quality of care is variable because the government priority has been the quantity of services (as opposed to the quality).

Development of a national palliative care consensus:

There is no official consensus about the National Palliative Care Program but the current law (2012) was approved by all parties represented in Parliament.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

There have been no such meetings, although the National Palliative Care Association has played a very important role in meeting with the Portuguese government.

Development of an advocacy framework for integrating palliative care into the health care system:

The 2012 Law integrates palliative care into the health care system.

Strategies to improve political awareness and government recognition of palliative care:

The former President of the National Palliative Care Association (2006-2011) is now a Deputy Minister in Parliament and is attempting to ensure that palliative care is placed firmly on the agenda of the Portuguese health care system.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

The English Ambassador provided one funding initiative and one donor supported a fellowship for palliative care research and education through the National Palliative Care Association.

Involvement with the European Union in relation to hospice and palliative care initiatives:

There is no information available at this time.

Development of initiatives framing palliative care as a 'human right':

Some interviews in the mass media have framed palliative care as a 'human right'.

General legislation relating to palliative care:

The National Palliative Care Program (2012).

Published national documents relating to palliative care standards and norms:

- Printed: Organization of Services of Palliative Care (APCP Recommendations) and Quality Criteria for Palliative Care Services (APCP Recommendations) (2006).
- Online: <http://www.apcp.com.pt/documentao/diretivasrecomendaesapcp.html> (2006).

National Plan or Strategy of Palliative Care:

The National Palliative Care Program (2012).

National Cancer Control Strategy:

The overall objective of the National Cancer Control Program consists of reducing the incidence of cancer mortality in Portugal through a set of measures that include: education and health promotion; screening and early diagnosis; improved quality of diagnosis; and proper and timely treatment. The program seeks the integration of various modalities of cancer treatment (including rehabilitation and palliative care).

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy (but it does not contain an explicit reference to the provision of palliative care).

National Primary Health Care Strategy:

There is a National Primary Health Care Strategy (but it does not contain an explicit reference to the provision of palliative care).

Designated policy maker for the delivery of palliative care services:

The Portuguese government has promoted a new Base Law for the development of a National Palliative Care Network.

Department of Health specific responsibility for the delivery of palliative care services:

- The Mission Unit for Integrated Continuity of Care is the structure responsible for palliative care development.
- The law on palliative care (2012) created a national coordinating committee.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

There are some specific laws about the prescription of opioids (Despachos 30993/2008 e 30994/2008).

Funding of palliative care services:

- There is partial payment required for palliative care consultation.
- No payment is required for palliative care hospitalisation.
- There is partial payment required for palliative care medications.

An important development has been the 2012 Law on Palliative Care establishing the National Network for Palliative Care. The EAPC Congress in Lisbon (May 2011) increased the visibility of the National Association of Palliative Care

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

The public have more awareness about the importance of palliative care; an increasing number of people consider palliative care as a basic right and not a privilege.

Major public discussion, debate or controversy about hospice and palliative care:

There has been major public discussion about hospice and palliative care.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

Some policy and opinion makers have discussed palliative care issues (the mass media also).

Hospice or palliative care 'success' stories:

Several patients and their families have shared their experiences in the mass media, highlighting the improvement in their quality of life due to palliative care initiatives.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is a little active public debate on the legalization of euthanasia.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

- The implementation of the new Base Law from January 2013
- This new Base Law and some initiatives to promote quality (a Doctoral Thesis in Quality Indicators for Palliative Care Services, for example) will result in improvements in palliative care in the future.

Most significant issues facing hospice and palliative care in the next three years:

- The quality of care provided; specialized education in palliative care for healthcare professionals; increasing the number of healthcare professional engaged in palliative care.
- The National Association of Palliative Care has been communicating with educational institutions and policy makers to try and resolve some of these issues.

Implications for palliative care relating to the current economic crisis:

There is an opportunity to develop palliative care during the current economic crisis because it involves a more rational use of scarce resources.

The public have more awareness about the importance of palliative care; an increasing number of people consider palliative care as a basic right and not a privilege

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Republic of Macedonia¹

NATIONAL ASSOCIATION

National Association for Palliative Care, Macedonia

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|--|-----------------------|
| Volunteer hospice team | 2 (n/a) |
| Hospital palliative care support team | 4 (n/a) |
| Home palliative care support team | 1 |
| Mixed palliative care support team | 5 (75) |
| Palliative care units in tertiary hospitals | 8 (20) |
| Palliative care units in non-tertiary hospitals | 1 (200) |
| Inpatient hospice | 3 (350) |
| Day hospice/day care centre | 3 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Ministry of Health of Republic of Macedonia; Public Health Institution Hospice for Palliative Care Skopje and Bitola; Paediatric Clinic Skopje; public and privately owned homes/institutions for the elderly at the local level; Institute of Gerontology-Hospice Sue Ryder Skopje; Haematology clinic; and the Oncology clinic.
- Analysis of the situation of the state of palliative care in Republic of Macedonia (2008).

Additional comments:

- The number of volunteers varies over different periods of time (approximately 5-10 for each team). The volunteers undertake work on this basis in order to secure permanent employment in these institutions.
- There are hospices in Skopje and Bitola (Sue Ryder), and the Institute of Gerontology in Skopje (Oncology clinic).

- The National Strategy for Palliative Care aims to expand the network of home palliative care support teams throughout Macedonia.
- There are five mixed palliative care support teams working within the Sue Ryder hospices.
- The Institute of Gerontology (Skopje) has 100 beds for acute patients and 100 beds for chronically ill patients (it is mainly used for patients with chronically-progressive disease).
- The two hospices opened by "Sue Ryder" (Skopje, 1998 and Bitola, 2005) are for patients who are terminally-ill from malignant disease, or have chronically-progressive disease.
- There are day care centers in the Institute of Gerontology and the two "Sue Ryder" hospices.
- New users of palliative care services total approximately 1,000 patients annually.
- The hospices cover 30% of all registered terminally-ill patients, with 18 days of treatment on average.
- Of all patients treated in hospice (approximately 600 per year) 50% of them die in the hospices.
- The domiciliary care teams cover only 1% of the total need; patients die at home within an average of one year from when treatment commences.
- Some palliative care services are provided at the primary level by family doctors (Legislative for National Health Services article.32/2000). The services are provided in the home of terminally-ill patients.
- Specialized units for palliative care in hospital departments have optimal availability of 0.004% hospital beds per 1000 patients.
- Professional resources available in hospices are one doctor and five nurses per 10 beds.

Palliative care services for children:

There is one paediatric volunteer hospice team (5 beds), one paediatric hospital palliative care support team (5 beds), and one paediatric palliative care unit in a tertiary hospital (5 beds).

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|------|--|
| 1998 | The first hospice in the Republic of Macedonia is opened. |
| 2000 | The results from the research forum on the "Application and availability of opioids for terminally-ill patients" are published. |
| 2001 | The second hospice in the Republic of Macedonia is opened. |
| 2003 | Palliative care becomes an integral part of the health care system of Macedonia. |
| 2004 | Publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organization of palliative care) is officially marked by the hospice for specialist palliative care Sue Ryder Care. |
| 2005 | Interdisciplinary teams for palliative care are created and the domiciliary palliative care service is developed. |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- Adopting the National Strategy for Palliative Care produced by the Ministry of Health, Government of the Republic of Macedonia.
- The need to raise awareness about palliative care and gain attention for the need for appropriate services for people who require this type of care,
- Developing a palliative care network throughout Macedonia to be supported and financed by the Ministry of Health of the Republic of Macedonia.
- In 2005, thanks to the "Sue Ryder Foundation" from England, palliative care began to be developed in Macedonia; project activities involved collaboration with the Ministry of Health. From this successful collaboration, two hospices were built, fully equipped and made functional (in Skopje and Bitola). At the same time, in collaboration with "Soros" Foundation, palliative care education was made available to healthcare professionals working in this area.
- A new project was developed in Skopje: "Domiciliary palliative care". It is significant that these projects were implemented in the State Health Care System and financed by the Ministry of Health from the very beginning and that they are therefore sustainable.

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has remained the same.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: There is no information available at this time.
- Nursing homes: There is no information available at this time.
- Residential homes for the elderly: These institutions are the designated institutions for the "end of life" phase (Analysis of the situation in the old people's home and geriatric home, 2005).
- Other community settings: There is no information available at this time.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

Palliative care is provided for patients that are in the terminal phase of malignant disease, and for patients with chronically-progressive disease.

Perceived barriers to the development of hospice and palliative care:

- Lack of finance.
- Lack of palliative care education.
- No development in basic palliative care legislation.

Perceived opportunities for the development of hospice and palliative care:

- Limited possibilities for palliative care education.
- Limited possibilities for improving domiciliary palliative care.
- Possible contracting with pharmaceutical companies to provide the necessary medication for palliative care.

Other issues relevant to the development of hospice and palliative care:

The experience exchange between "Sue Ryder" and "Soros" Foundation on palliative care education and training has contributed to the development of the discipline in Macedonia (since January 2006).

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

The National Association for Palliative Care of Republic of Macedonia (Zdruzenie za Paliativna zastita pri Makedonsko lekarsko drustvo, Skopje, Republic of Macedonia) was formed in 2001; the association has a website (<http://mld.org.mk/>), and is representative of the whole country.

Directory or catalogue of palliative care services:

There are printed brochures and leaflets on palliative care for patients and families (available since 2003).

Congresses, scientific meetings or scientific journals in palliative care:

There are bi-annual national palliative care symposia and workshops (attended by approximately 50 participants).

Palliative care research capacity:

There is no information available at this time.

Palliative care collaboration:

- There is collaboration with all other Sue Ryder hospices around the world (and a number of other palliative care institutions).
- Sue Ryder Care was the first institution of its kind in Macedonia, developing a model for other institutions in relation to palliative care. This was achieved in collaboration with the government of Republic of Macedonia (Ministry of Health).
- Macedonia celebrates each World Hospice and Palliative Care Day by disseminating information about the development of palliative care in the country during that year. Representatives of "Sue Ryder" talk with patients and their families about ways in which the quality of palliative care provision can be improved. Awareness about palliative care is raised amongst the general public through both printed and electronic media.
- There is international communication and cooperation through regional institutions and associations of palliative care - EU, MMF, Stability pact, Brussels, and the EU Counsel, have all worked closely with "Sue Ryder, "Soros" and other NGO's involved in palliative care.

Worldwide palliative care alliance level of development:

4B (Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

There is ongoing training and education in palliative care for Macedonian health-care professionals (in collaboration with “Soros” Foundation). “Sue Ryder” is working on a national program for education for family doctors, social workers and volunteers. The organization is currently attempting to raise funds for this initiative (this is an ongoing process – the initiative is not yet functional).

Specific developments in under-graduate palliative care education initiatives:

- **Medicine:** Palliative care is included in the educational program for doctors at the Medical High School. There is an ongoing effort to develop a palliative care program at the Medical Faculty in Skopje, Macedonia.
- **Nursing:** There is an existing palliative care education program for nurses in the 3rd year at Medical High School (2-3 lectures in “Oncology and Palliative therapy”).
- **Social work:** A national program for the education of social workers in palliative care needs to be adopted and implemented (produced by the Department of Social Policy as a part of the Philosophical Faculty in Skopje).
- **Other professions:** A national program for education in palliative care needs to be adopted and implemented for other healthcare professionals, volunteers, and family members.

Specific developments in post-graduate palliative care education initiatives:

- **Medicine:** There is no information available at this time.
- **Nursing:** There is no information available at this time.
- **Social work:** There is no information available at this time.
- **Other professions:** There is no information available at this time.

Translation of palliative care documents or other materials:

Some manuals and brochures have been translated for patients and their families. The books that are used by healthcare professionals are usually in English.

Initiatives to develop healthcare professional leadership in palliative care:

There are no such initiatives in the Medical Faculties in Macedonia.

Officially recognized medical certification:

- Palliative care is mainly practiced by doctors that have had specialized education in palliative care: Oncologists; Anaesthesiologists; Haematologists; and doctors of Internal Medicine.
- All public health institutions are accredited for the healthcare services that they provide, including palliative care from the Medical Chamber of Doctors of Republic of Macedonia. The teams have received palliative care education from the “Soros” Foundation and “Sue Ryder” Foundation, in conjunction with the Faculty of Medicine and the National Palliative Care Association of Macedonia. The National Strategy for Palliative Care has been adopted by the government of Republic of Macedonia, and is expected to result in the development of postgraduate studies and specializations in palliative care.

Capacity of palliative care workforce training in Universities and Medical Schools:

- The Republic of Macedonia has three medical schools of which one has Palliative Medicine as a mandatory component - Faculty for Medical Nurses, Bitola (Source: Ministry of Education of Republic of Macedonia).
- There is one full Professor of Palliative Medicine (Faculty for Medical Nurses, Bitola) and two assistant professors.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- Most essential pain medications are not available in Macedonia.
- “Sue Ryder” is in negotiation with the national pharmaceutical company “Alkaloid” and the Bureau for Medication at the Ministry of Health on this subject (but there has been little positive outcome to date).
- No Government or private sector entity or pharmaceutical company has shown any interest in producing or importing any of the essential medications that are required in palliative care (especially the ones for pain control).

Developments/opportunities/barriers relating to the accessibility of essential medications:

As above.

Developments/opportunities/barriers relating to the affordability of essential medications:

Medications on the list of the National Health Care System are not on the WHO list of essential medications. Some essential medications can be found in private pharmacies, but they are very expensive and therefore not affordable for most patients.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

“Sue Ryder” is developing an initiative to expand the list of essential medications that are available to healthcare professionals working in palliative care.

Initiatives to promote attitudinal change in relation to ‘opiophobia’:

There is no information available at this time.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

In Macedonia, all citizens have basic health insurance that includes the right to opioid medication on the basis that a physician recommends it as necessary for their treatment.

Initiatives that consider access to essential medication as a legal and human right:

There is no initiative as such because medication is available if a physician recommends it as necessary for treatment.

Thanks to the Sue Ryder Foundation, palliative care continues to be developed in Macedonia; a palliative care network throughout the country is beginning to be supported and financed by the Ministry of Health

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

"Sue Ryder" is currently working on improving the current legislation relating to palliative care: in particular, the general health care services that are specific to palliative care services.

The impact of these policy changes and ways in which they have been important:

Based on the recommendations of the EU Council of Ministries for Palliative Care, the National Strategy for Palliative Care, evidence-based medicine and experiences gained by "Sue Ryder", palliative care has been implemented into the national health care system of Republic of Macedonia. This was achieved following many years of campaigning towards raising awareness of the needs of people who require this type of care (and their families).

Development of a national palliative care consensus:

"Sue Ryder" is working on developing national standards for palliative care so the best possible quality of service can be provided (despite limited financial resources).

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

"Sue Ryder" has had significant meetings with stakeholders (NGOs) and governmental policy makers to develop palliative care strategies.

Development of an advocacy framework for integrating palliative care into the health care system:

Palliative Care has been integrated into the national health care system in Macedonia since the opening of the first hospice to provide palliative care in 1997 (2004 article 101 in the legislative for health care).

Strategies to improve political awareness and government recognition of palliative care:

"Sue Ryder" started basic research projects that provided an indication that there was a growing group of people requiring palliative care. In the beginning, these were usually elderly people in geriatric wards and institutions, but it became more apparent that an increasing number of people were in dire need of such services (particularly those in the terminal phase of malignant disease). This provided evidence and data for the policy makers that resulted in legislation that was subsequently adopted and implemented by the Macedonian Government.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

During the period of development and implementation of palliative care, many people from the private business sector, NGO's, and individuals provided financial contributions. The most significant financial support came from the Government of Republic of Macedonia, in relation to implementing and financing palliative care services. In the NGO sector, major support came from the "Sue Ryder" Foundation which donated financial aid to build and make functional the two hospices in Skopje and Bitola.

Involvement with the European Union in relation to hospice and palliative care initiatives:

"Sue Ryder" is in communication with the European Union Institutions and Associations regarding the development of palliative care in Macedonia.

Development of initiatives framing palliative care as a 'human right':

Based on the legislation that has already been passed in Macedonia, palliative care is already considered as a basic human right for every person in the country.

General legislation relating to palliative care:

The legislation relating to palliative care is integrated into general health care legislation. The National Strategy for Palliative Care was adopted by the Government of Republic of Macedonia in 2007.

Published national documents relating to palliative care standards and norms:

Printed National Standards for Palliative Care were first published in 1998. Revised standards have been published annually since 2002 (the text is adopted to incorporate new data based on medical evidence).

National Plan or Strategy of Palliative Care:

- There is a National Strategy for Palliative Care for Republic of Macedonia and palliative care is integrated into the national health care system (strategic priorities and activities relating to the development of palliative care in the country).
- However, the National Strategy for Palliative care (2010-2020) adopted by the Government of Republic of Macedonia –Ministry of Health (April, 2010) has not resulted in the expected level of development defined within health policy (Introduction I to the report for 2011 regarding Palliative Care in Macedonia).

National Cancer Control Strategy:

There is a registry for malignant diseases, but this has not been updated since 2006.

National HIV/AIDS Strategy:

This strategy is contained within the National Strategy for Palliative Care in Macedonia.

National Primary Health Care Strategy:

The developing concept of the National Strategy for Palliative Care in Macedonia gives priority to family doctors in terms of their training and education, and their work with patients in the terminal stage of disease.

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

The Department of Health has specific responsibility for the delivery of palliative care services; it is in the legislation and it is described in the National Strategy for Palliative Care.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is an internal audit conducted by the Ministry of Health in Macedonia that screens all departments and organizations providing healthcare.

Opioid legislation/Pain guidelines:

- The provision of opioids is regulated by the Ministry of Health, and there is a National Coordinator for Drugs. The Commission of Drugs and Psychotropic Substances are responsible for the supervision, administration and legal provision of opioids, as a part of the Ministry of Health of Republic of Macedonia.
- All health institutions regulate all acquisitions of opioids, and there is special documentation for this.
- There are printed pain guidelines: a protocol and guidelines for pain management exist in the institutions providing palliative care.

Funding of palliative care services:

- Payment for palliative care consultation, hospitalisation and medications is covered by the health insurance fund.
- There is a DRG system in place in relation to payment for specific disease.
- Besides the guaranteed health care services in the national health care system, the national health care fund finances special services for palliative care (20 Euros per patient).

The exchange of experience between Sue Ryder Foundation and Soros Foundation on palliative care education and training for healthcare professionals has contributed to the development of the discipline in Macedonia

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:
There is increased awareness about the work of hospices, and increased understanding about the care and services they provide to patients and their families.

Major public discussion, debate or controversy about hospice and palliative care:

There has not been any controversial debate or controversy about palliative care; on the contrary, professional and public opinion is rather positive and supports the work of the palliative care institutions.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

Overall awareness and understanding of hospice and palliative care amongst the public is quite high, and all relevant professionals have understanding and support for development of the discipline.

Hospice or palliative care 'success' stories:

There are many 'success' stories about the services provided by palliative care institutions and healthcare professionals in Macedonia (including a higher rate of patients that have received palliative care).

Initiatives seeking the legalisation of euthanasia or assisted dying:

No such initiative has been requested from the patients, their families, health care professionals or the general public.

A National Strategy for Palliative Care has been produced by the Ministry of Health. Awareness has been raised about palliative care and the need for appropriate services for people who require this type of care

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

- There is a need to fulfil the requirements of the national strategy regarding the development of palliative care throughout Macedonia (especially the development of domiciliary palliative care).
- Development of education programs in the field of palliative care, including pre- and post-graduate studies for doctors, nurses, social care workers etc.
- Promotion of the results of research demonstrating the need for palliative care services, and their implementation in the national health care system (flexible model of allocation of resources).

Most significant issues facing hospice and palliative care in the next three years:

- Palliative care in Republic of Macedonia has become a problematic challenge, since the possibilities of the State to support patients and their families have become disproportionate in relation to the need for this type of care. The growing trend of aging of the population, and higher number of patients with malignant disease and chronically-progressive disease represents an absolute priority in health policy (Introduction I to the report for 2011 regarding Palliative Care in Macedonia).
- The biggest issue facing hospice and palliative care is the issue of "accepting death" as a natural process; knowing that hospice and palliative care institutions exist to improve the quality of life in this final phase, and helping the family and the patient come to terms with the processes that they are going through. Most terminally-ill patients have no prior knowledge or preparation by the family doctor or oncologist about their impending death and possess no information about which phase of the disease trajectory they are in.

Implications for palliative care relating to the current economic crisis:

The economic challenges will be reflected in the quality of the services and care that is provided. This is also applicable to the development of national palliative care projects in Macedonia.

References

There are no known publications at this time.

Republic of Moldova¹

NATIONAL ASSOCIATION

Hospice Palliative Care Society

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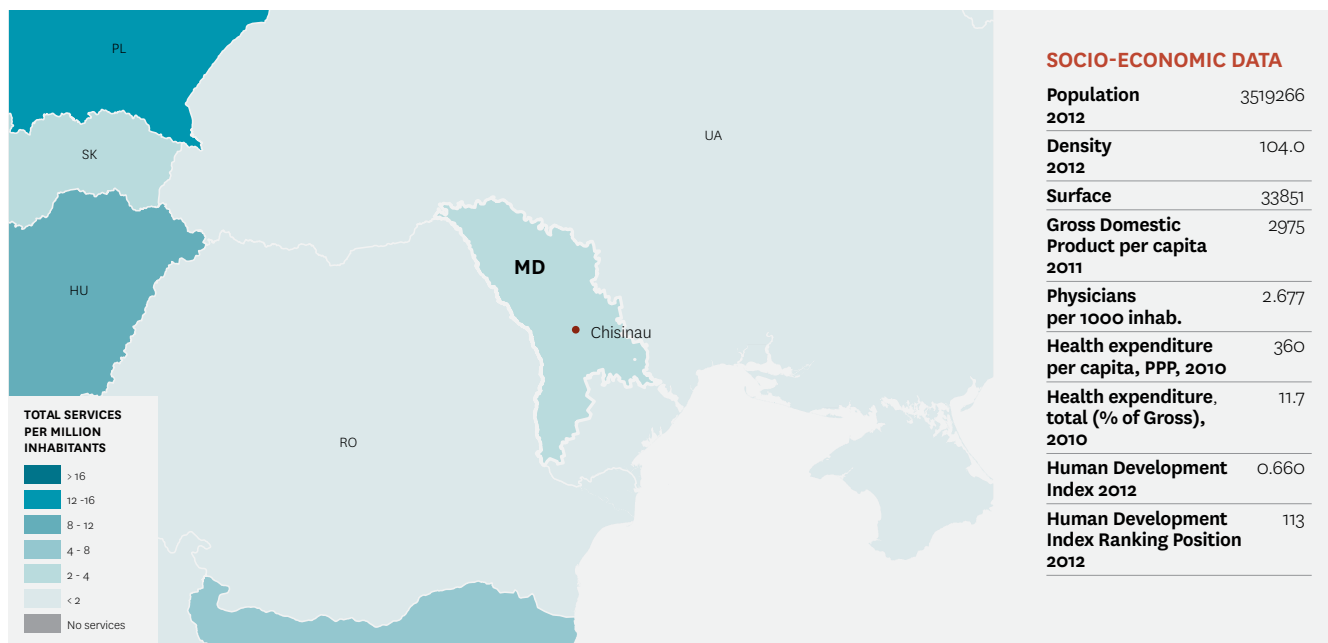
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 1 |
| Home palliative care support team | 5 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 1 (30) |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 1 (12) |
| Day hospice/day care centre | 0 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Vadim Pogonet, MEDICAL DOCTOR
- Valerian Isaac, MEDICAL DOCTOR
- Maria Chiose, REGISTERED NURSE
- Anatolie Beresteanu, MEDICAL DOCTOR
- Livia Gudima, MEDICAL DOCTOR
- Elena Stempovscaia, REGISTERED NURSE
- Vasile Suruceanu, MEDICAL DOCTOR

Additional comments:

- Teams are placed in: Chisinau (capital) - "Angelus-Moldova" (adults and children) (services commenced November 2001); Taraclia town - "Angelus-Taraclia" (services commenced October 2009); Cismisla town - "Angelus-Cismisla" (services commenced October 2010); Ocnita town - "Angelus-Ocnita" (services commenced October 2010); Zurbesti village - Hospice "Carolina de Nord" (adults and children) (services commenced 1999).
- The only palliative care inpatient unit is the 30-bed unit in the tertiary hospital in Chisinau (service commenced September 2011).
- The only hospice in Moldova cares mainly for cancer patients (95% - both adults and children). In principal, patients are referred from Straseni district, and rarely from Chisinau city or any other country district (and then only if opioids can be supplied).

Palliative care services for children:

There are two paediatric home palliative care support teams, one paediatric inpatient hospice (3 beds) and one paediatric day hospice.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|-------------|--|
| 2000 | Medico-Social Foundation "Angelus-Moldova" commenced work in Chisinau. |
| 2003 | "Moldova Hospice - Palliative Care Society" was formed. |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

The legislative framework for palliative care has been approved:

- The concept of palliative care
- The regulation of palliative care services
- National standards in palliative care
- National Clinical Protocols in palliative care
- The costs of palliative care services
- Curriculum in palliative care education for doctors and nurses

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has improved in the area of legislation; there has been some improvement in the areas of availability and accessibility of opioids and palliative care education and training.

Development of hospice and palliative care in different health and social care settings:

Hospitals:

- There is a hospice in the Zubresti region
- Home care services are provided by Foundation "Angelus Moldova" in Chisinau
- There are hospice affiliates – "Angelus Moldova" in the Comrat, Cimislia, and Ocnita regions
- There is a 30-bed ward for palliative care at the country level
- There is a multidisciplinary mobile team in the Oncological Institute
- Home palliative care services are provided by HOMECARE Association and Caritas Moldova
- Nursing homes: There is no palliative care provision in these settings
- Residential homes for the elderly: There is no palliative care provision in these settings
- Other community settings: There is no information available at this time.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

- The first hospital ward providing palliative care for HIV/AIDS patients is operating within the Dermato-venerology Hospital
- Home palliative care services for HIV/AIDS patients are provided in the Balti region.

Perceived barriers to the development of hospice and palliative care:

- Lack of financial resources.
- Lack of adequate funding for palliative care services provided by NGOs.
- Insufficient information about palliative care services.
- Absence of a National Strategy of Palliative Care Development in Moldova.
- Palliative care is not recognised as a medical speciality in Moldova.
- There is only one opportunity to achieve a Diploma in palliative care (Post-graduate Diploma for Nurses).
- Most palliative care services are predominantly provided by NGOs.
- Opioid availability and accessibility is still a problematic issue.
- Lack of materials and supplies for palliative care (wound care, colostomies, etc.).

Perceived opportunities for the development of hospice and palliative care:

- The enhancing of palliative care services in the Republic of Moldova
- The building of a new type of hospice in Chisinau city
- The training of multidisciplinary teams
- Including the strategy for palliative care development as part of the strategy for oncology development in Moldova
- Improving the visibility and quality of services provided
- Increasing the number and forms of palliative care provision

Other issues relevant to the development of hospice and palliative care:

- Lack of social support from the Ministry of Labour, Social Protection and Family. Currently, palliative care services are provided by the Ministry of Health.
- Issues relating to the use of oral morphine remain unresolved.

The legislative framework for palliative care has been improved: the concept of palliative care has also improved, and regulation of palliative care services and the development of National Standards in Palliative Care have taken place

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- The National Society "Hospice-Palliative Care" of the Republic of Moldova (Societatea Națională "Hospice-Îngrijiri Palliative" a Republicii Moldova), was formed in August 2003 and is representative of the whole country.
- The National Association for Palliative Care (Asociația Națională de Tratatament Palliativ), was formed in November 2011, and is also representative of the whole country.

Directory or catalogue of palliative care services:

There is no directory or catalogue of palliative care services at this time. However, please refer to:

<http://www.hospiceangelus.md/en/main.html> - Hospice "Angelus" home care service

<http://onco.md/TERAPIE-17.html> - mobile palliative care team of the Institute of Oncology

http://www.respi.org/hom_ro.html - Society "Second breath" - palliative home care for elderly cancer patients

Congresses, scientific meetings or scientific journals in palliative care:

- In 2003 and 2006 (then annually since 2009), national conferences relating to different topics in palliative care have been organised by the Charity Foundation for Public Health "Angelus-Moldova" in collaboration with the National Association for Palliative Care (attended by approximately 100 participants); 32 one-day seminars on palliative care issues and chronic pain control in cancer have been held in all regional centres.
- Other organisations such as "Second Breath", Hospice "Carolina de Nord", and the National Society "Hospice-Palliative Care" also organise national conferences and events that aim to disseminate information about palliative care among local and regional communities.

Palliative care research capacity:

- All palliative care research activities are conducted on a basic level and take place in each individual organisation.
- Vadim Pogonet, medical doctor at the Oncological Institute of Moldova (vad-imp@gmail.com).
- Medical staff of the Charity Foundation for Public Health "Angelus-Moldova" (info@hospiceangelus.md).
- "The perception of cancer pain control quality by district oncologists in Republic of Moldova". Poster presented at the 12th congress of the EAPC, Lisbon (May 2011)
- A study "The End-of-Life Practices in Moldova": Authors - A. Kellehear, V. Pogonet, R. Mindruta, V. Gorelco, 2011 (UNESCO Moldova) was completed during 2010 - 2011. The book "Care of the dying in the Republic of Moldova", based on the study results was published in 2011.

Palliative care collaboration:

- Charity Foundation for Public Health "Angelus-Moldova", Hospice "Angelus" is in partnership with "Angelus-Taraclia", "Angelus-Cimislia" and "Angelus-Ocnita"; as well as with the Department of Palliative Care at the Clinical Hospital nr. 4 in Chisinau and Hospice "Carolina de Nord". Hospice "Angelus" provides educational support (delivering lectures) in basic palliative care to the staff of "Angelus-Taraclia", "Angelus-Cimislia" and "Angelus-Ocnita", as well as providing consultative support in the management of difficult clinical cases. Organizations are invited to take part in educational events (including national conferences) and are provided with assistance in the form of medical consumables and accessories. Where required, patients from the home-based palliative care services can be transferred to the Department of Palliative Care at Clinical Hospital nr. 4 or to Hospice "Carolina de Nord".
- Charity Foundation for Public Health "Angelus-Moldova", Hospice "Angelus" is in a twinning collaboration with Dorothy House Hospice (Bath, United Kingdom). Hospice "Angelus" staff and professionals from other palliative care organisations benefit from palliative care education training programs provided by Dorothy House Hospice staff who also participate in national conferences held in Chisinau; some medical consumables and accessories are also provided by Dorothy House Hospice.
- The staff of Greensboro Hospice (USA) provided training for staff of Hospice "Carolina de Nord" and helped to launch the hospice service by donating beds and organising palliative care provision for children and adults - including a home-based service, day care center and inpatient department.
- Many pioneers of palliative care in Moldova are non-governmental organisations: in 1999, "Second breath" in Balti began working with elderly people and persons living with HIV/AIDS; also in 1999, Hospice "Carolina de Nord" in Zubresti village began working with both cancer and non-cancer patients (adults and children); and in 2001, Charity Foundation for Public Health "Angelus-Moldova" in Chisinau began working with terminally-ill adults (cancer).
- "Soros-Moldova" Foundation financially supports events organised by the National Society "Hospice-Palliative Care" and the National Association of Palliative Care to promote World Hospice and Palliative Care Day. Hospice "Carolina de Nord", Hospice "Angelus-Taraclia", Hospice "Angelus-Cimislia", Hospice "Angelus-Ocnita", and Charity Foundation for Public Health "Angelus-Moldova" annually organize events to promote World Hospice and Palliative Care Day.
- There has been continuous support from Open Society Institute and Soros Foundation Moldova in supporting the development of palliative care initiatives in the country (developing a multidisciplinary palliative care team in the Institute of Oncology, opioid legislation changes, elaboration of costs for palliative care services, supporting initiative groups at the Ministry of Health, training and education, participation at scientific meetings and workshops in palliative care)
- Collaboration with Institute for Palliative Medicine, San Diego, California, USA in relation to the Leadership Development Initiative.
- Collaboration with Education Center "Casa Sperantei", Brasov, Romania in supporting training for colleagues working in the field of palliative care in Moldova
- Collaboration with National Commission of the Republic of Moldova (UNESCO) and the University of Bath, UK in supporting a study on end-of-life-care practices in Moldova.

Worldwide palliative care alliance level of development:

3A (Isolated palliative care provision).

The cost of palliative care services is being more accurately assessed. There is now a curriculum in palliative care for doctors and nurses. There has been some improvement in the area of availability and accessibility of opioids

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- Development of palliative care curricula for nurses and doctors.
- There are 25 national trainers in palliative care.
- Many palliative care teams have received training in Romania (Hospice Casa Sperantei, Brasov).
- There has been much palliative care training in all regions of Moldova (due to the support of SOROS Moldova).
- Palliative care for nurses is taught at the Continuous Training Centre (72 hours).
- Optional courses on pain management (covering cancer pain and palliative care) have been included in the curricula for 6th year medical students at the Department of Anaesthesiology and Reanimatology, University of Medicine and Pharmacy, Chisinau, Moldova since 2010.
- Courses on cancer pain for oncologists have been provided at the Institute of Oncology since 2011.
- Courses on cancer pain for family doctors have been provided in Chisinau since 2012.
- Presentation of institutional protocols "Cancer pain" have been provided for family physicians in four regions of Moldova since 2012.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Palliative care is included in the curricula for 5th year medical students at the Medical University; it is also taught in the Family Medicine and Oncology Departments.
- Nursing: Palliative care is included in the curricula for 5th year nursing students at the Medical University; it is also taught in the Family Medicine and Oncology Departments.
- Social work: Palliative care is included in the curricula for 5th year social work students at the Medical University; it is also taught in the Family Medicine and Oncology Departments.
- Other professions: Palliative care is included in the curricula for 5th year students (other professions) at the Medical University; it is also taught in the Family Medicine and Oncology Departments.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: Palliative care is included in the curricula for 5th year medical students at the Medical University; it is also taught in the Family Medicine and Oncology Departments at the University of Medicine and Pharmacy (refresher courses for family doctors are also available).
- Nursing: Palliative care is included in the curricula for 5th year nursing students at the Medical University; it is also taught in the Family Medicine and Oncology Departments. Palliative care refresher courses for nurses are provided at postgraduate level.
- Social work: Palliative care is included in the curricula for 5th year social work students at the Medical University; it is also taught in the Family Medicine and Oncology Departments.
- Other professions: Palliative care is included in the curricula for 5th year students (other professions) at the Medical University; it is also taught in the Family Medicine and Oncology Departments.

Translation of palliative care documents or other materials:

Two WHO publications have been translated.

Initiatives to develop healthcare professional leadership in palliative care:

Based on an initiative from the Hospice Angelus Moldova Foundation, five palliative care leaders received training in this area; in another initiative in collaboration with the Hospice Palliative Care Society, a further twelve palliative care leaders were trained in this area.

Officially recognized medical certification:

- There is no officially recognized medical certification for doctors.
- There is a form of certification for nurses working in palliative care (a post-graduate course).

Capacity of palliative care workforce training in Universities and Medical Schools:

- The Republic of Moldova has six medical schools (five medical colleges and one Medical university), of which five have palliative care as a mandatory component and one where palliative care is available as an optional component.
- In medical colleges, palliative care is not a separate subject but is included as a part of other medical disciplines.
- Palliative care for 5th year medical students at Medical University involves 36 hours of theory and 36 hours of practical skills.
- In 2009, there were 19 trainers in palliative care who were awarded a special certificate "National trainer in palliative care" approved by the Ministry of Health; trainers include doctors, nurses and a psychologist.

The first hospital ward providing palliative care for HIV/AIDS patients is operating within the Dermato-venerology Hospital. Home palliative care services for HIV/AIDS patients have begun to be provided in the Balti region

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- The availability of essential medications is satisfactory, although there are unresolved issues relating to the use of morphine. For patients in rural areas, there is a complicated mechanism in regard to the prescribing of opioids.
- Proposals submitted by the Hospice Palliative Care Society to make changes in opioid legislation were accepted and introduced into Moldovan law.
- Several documents that guide the availability of essential medicines for palliative care have recently been approved; there is now no maximum dose of opioids per prescription; the availability of a prescription for opioids is now 14 days; and the amount of opioids that can be prescribed is for 30 days of treatment.
- Only one oral form of opioid is available in Moldova - 10 mg slow-release morphine tablets. No oral liquid solution of opioids is available for children.
- There is therefore a need to make other forms of oral morphine available in the country – immediate-release forms (10mg and 30mg), 30mg and 60mg slow-release tablets and oral opioid solutions for children. There is also a need for new instructions on returning unused oral formulations.
- There are no alternative opioids to morphine available for treating strong pain.

Developments/opportunities/barriers relating to the accessibility of essential medications:

There is no information available at this time.

Developments/opportunities/barriers relating to the affordability of essential medications:

Morphine is available for free for cancer patients.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

A letter with a request for different oral formulations of strong opioids for adults and children in Moldova was submitted to the main oncologist of the country and the National Drugs Agency by the mobile multidisciplinary palliative care team of the Institute of Oncology in November 2012.

Initiatives to promote attitudinal change in relation to 'opiophobia':

Courses for oncologists and family physicians on the treatment of cancer pain and new opioid policy are planned for 2013 by the mobile multidisciplinary palliative care team of the Institute of Oncology and Hospice Angelus Moldova Foundation.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

Several palliative care services in Moldova (home care service, inpatient unit and hospice) have been subcontracted by the National Insurance Company since 2011

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

The following regulatory documents for palliative care have been approved:

- "The Concept of Palliative Care".
- "The Regulation of Palliative Care Services".
- "National Standards in Palliative Care".
- Four National Clinical Protocols for Palliative Care (cancer pain, gastrointestinal pathology, dyspnoea and terminal care, skin problems).
- "The Costs of Palliative Care Services".

The impact of these policy changes and ways in which they have been important:

- Several palliative care services in Moldova (home care service, inpatient unit and hospice) have been subcontracted by the National Insurance Company since 2011.
- Palliative care services are mentioned more frequently as part of National Health Strategies and Programs (Strategy of Development of Oncology Services, Strategy of Cancer Prevention, etc.)
- Palliative Care as a specialty is gaining more credibility and importance in the medical world.

Development of a national palliative care consensus:

- A national palliative care consensus has been developed and approved within the range of relevant legislation.
- There are two National Palliative Care Associations with similar goals.
- However, there is a need for more communication between organisations that promote or provide palliative care in order to achieve common goals and objectives.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

At the Hospice Palliative Care Society (12 organizations that work in the area of palliative care), there have been significant meetings held on a monthly basis with representatives of the Ministry of Health, and the National Health Insurance Company. When drafting palliative care legislation, NGOs worked with the Ministry of Health, Soros Foundation Moldova, the Medicines Agency, and the Centre for Health Management. Those meetings preceded the majority of policy changes in the country in the field of palliative care.

Development of an advocacy framework for integrating palliative care into the health care system:

Training has been provided on lobbying and advocating for NGOs that work in palliative care. Examples of lobbying include National Health Policy development (where palliative care was introduced), and lobbying of local authorities to expand palliative care services.

Strategies to improve political awareness and government recognition of palliative care:

The concept of palliative care was included in the National Health Policy and put on the agenda of Ministry of Health strategies and plans to provide a range of activities to develop palliative care services. The Ministry of Health recognizes palliative care and works actively with NGOs from this area.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

Palliative care services have been implemented with the support of many sponsors. Recently, the Ministry of Health has recalculated the cost of hospice services provided by the Department of Palliative Care, which will be paid for by the Health Insurance Company. Home care services are funded by sponsors from the Netherlands, Austria, and United Kingdom.

Involvement with the European Union in relation to hospice and palliative care initiatives:

European countries that are mainly involved in supporting the hospice and palliative care movement in Moldova include the United Kingdom, the Netherlands, Romania, Austria and Poland.

Development of initiatives framing palliative care as a 'human right':

Initiatives framing palliative care as a 'human right' are at a very early stage, but there is a good legislative framework which allows for development of this concept.

General legislation relating to palliative care:

- Order nr. 234 (09.06.2008) - development of palliative care service in the Republic of Moldova.
- Order nr. 154 (01.06.2009) - organisation of palliative care services.
- Order nr. 875 (27.12.2010) - cost approval of an assisted case in medical palliative care provided in hospital/hospice for 2011.
- Order nr. (30.12.2010) - approval of the National Standards in Palliative Care.
- Order nr. 244 (31.03.2011) - organisation of palliative care service for persons with HIV/AIDS.
- Order nr. 60 (25.01.2012) - medical palliative care.
- Order nr. 197 (29.02.2012) - instructions approval about oral morphine administration.
- Order nr. 602 (18.06.2012) - prescribing and dispensing of medications.

Published national documents relating to palliative care standards and norms:

There are printed standards for palliative care for HIV/AIDS patients; also available online on the web site of the Ministry of Health of the Republic of Moldova (www.ms.gov.md); first edition 2008, latest edition 2010.

National Plan or Strategy of Palliative Care:

There is a National Plan or Strategy of Palliative Care in process.

National Cancer Control Strategy:

The National Cancer Control Strategy has been developed and awaits approval from the Ministry of Health.

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy.

National Primary Health Care Strategy:

The Program of Strategic Development of the Ministry of Health of the Republic of Moldova (2012–2014) includes the development of alternative services, domiciliary community care and palliative care services.

Designated policy maker for the delivery of palliative care services:

There is a designated policy maker for the delivery of palliative care services (see below).

Department of Health specific responsibility for the delivery of palliative care services:

The Department of Medical Integrated Services Management and Department of Planning and Regionalisation of Integral Healthcare Services at the Ministry of Health are responsible for development of alternative services, domiciliary community care and palliative care services (2012–2014).

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- Order nr. 602 (18.06.2012) - prescribing and dispensing of medications. Opioids can be prescribed (on a special prescription) for the amount required for treatment and for up to 30 days by a doctor of any specialty working in a medical institution (independently of type of ownership). Procurement is realised by the authorised pharmacy.
- Pain guidelines: www.ms.gov.md (web site of the Ministry of Health of the Republic of Moldova). National clinical protocol "Palliative care - pain in cancer" (2011). National clinical protocol "Palliative care in pressure sores" (2011). National clinical protocol "Palliative care in dyspnoea, terminal phase" (2011). National clinical protocol "Palliative care in gastrointestinal pathology" (2011). Guide in palliative care for family doctors (recommendations in clinical management) (2011).

Funding of palliative care services:

- There is no payment required for palliative care consultation.
- Partial payment may be required for palliative care hospitalisation: if a patient stays for more than 30 days per year in a specialised palliative care inpatient department (unless covered by the National Medical Insurance Company).
- Partial payment may be required for palliative care medications: oral or injectable Tramadol or immediate-release morphine depending on the pharmaceutical brand and country of import. In home-based care services, partial payment may be required for strong opioids: injectable slow-release Morphine and injectable slow-release Pantopon. Medications other than strong opioids are provided free of charge by home-based services.
- In 2011, the National Insurance Company allocated money to provide home care services (but not home-based palliative care services) from the Charity Foundation for Public Health "Angelus-Moldova", "Angelus-Taraclia", "Angelus-Cimislia" and "Angelus-Ocnita". In January 2012, new costs were approved for providing palliative care services: approximately 4.5 EUROS for one home-based palliative care visit provided by a mobile team; approximately 14 EUROS for one day/bed of inpatient palliative care provided in hospital/hospice; however, the home-based providers were not contracted in 2012. Their financial sources remain from donations, foreign grants and projects. The Department of Palliative Care at the Clinical Hospital nr. 4 and Hospice "Carolina de Nord" are financed by the National Insurance Company.

The Program of Strategic Development of the Ministry of Health of the Republic of Moldova (2012–2014) includes the development of alternative services, domiciliary community care and palliative care services

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

The visibility of palliative care services in Moldova is increasing. Patients more frequently enquire about the availability of palliative care services in hospitals and rural areas and healthcare professionals more frequently apply for consultations with palliative care teams and seek hospitalisation for their most needy patients.

Major public discussion, debate or controversy about hospice and palliative care:

There have been many round tables, seminars, and conferences with NGOs and other organisations: Ministry of Health, Ministry of Labour, Social Protection and Family and the National Insurance Company.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

Information bulletins

- TV Commercials
- TV programs
- Radio interviews

Hospice or palliative care 'success' stories:

Each organisation in the area of palliative care has had its success stories.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There are no initiatives seeking the legalisation of euthanasia or assisted dying; euthanasia is forbidden in Moldova.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

- Palliative care services need to be implemented in all regions of the country in the future (modern hospices and many other services). More palliative care experts are required.
- There is a need for a National Strategy on Developing Palliative Care Services in Moldova.
- The recognition of palliative care as a medical speciality would add important "legal" value to the development of the discipline in the country.

Most significant issues facing hospice and palliative care in the next three years:

- Lack of different type (and number) of palliative care services
- Palliative care is not a "prestigious" discipline
- Palliative care is not a government priority
- Lack of finance
- Lack of personnel
- The Hospice Palliative Care Society has a major role in the development and implementation of palliative care services in Moldova

Implications for palliative care relating to the current economic crisis:

Cutbacks in palliative care services. Due to the shortage of financial resources, the government may postpone approval of the National Cancer Control Strategy (which includes reference to palliative care).

References

Mosoiu, Daniela. January-February 2011. "European insight. Developing palliative care in Moldova: a top-down approach". *European Journal of Palliative Care*; 18 (1): 46-9.

There have been many round tables, seminars, and conferences with NGOs and other organisations: Ministry of Health, Ministry of Labour, Social Protection and Family and the National Insurance Company

Romania¹

NATIONAL ASSOCIATION

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 2 |
| Home palliative care support team | 15 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 5 (37) |
| Palliative care units in non-tertiary hospitals | 9 (320) |
| Inpatient hospice | 11 (139) |
| Day hospice/day care centre | 5 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Catalogul serviciilor de îngrijiri paliative din Romania 2010 (palliative care services in Romania 2010, electronic edition)
- Oana Donea
- ESMO (European Society for Medical Oncology): designated centers of integrated oncology and palliative care in 2010, Institute of Oncology, Bucharest www.spitalulslu.ro
- Vilnis Sosars/Development capacity of Palliative Care in the European Region. Catalan Institute of Oncology. WHO Regional Meeting 19-20 April, 2010. whocc.info@iconcologia.net. Presentation from Latvia. Data from the Ministry of Health (Reinis J)
- Malina Dumitrescu (personal communication)
- Deschiderea secției de Îngrijiri Paliative la Spitalul Codlea -16.01.12 (youtube)

Additional comments:

- An estimate cannot be provided for the number of volunteers - it is not something that people usually do. Because they need to have a stable economic level, they are not part of a culture that encourages voluntary work (voluntary work is neither organised nor supervised in Romania).
- It is estimated that hospital palliative care support teams provide some form of home-based care also. As none of the hospital palliative care support teams are exclusively hospital-based, they could also be considered as mixed palliative care support teams.
- It is possible that specific beds allocated for palliative care in tertiary hospitals are located in oncology departments.
- There are several new units to be opened in 2012 (for cancer and non-cancer patients).
- Day care centres include one for Alzheimer patients and one for HIV/AIDS patients in Bucharest.

Palliative care services for children:

There is one paediatric hospital palliative care support team, five paediatric home palliative care support teams, three paediatric inpatient hospices (20 beds) and five paediatric day care centres.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|------|--|
| 1992 | Hospice Casa Sperantei starts providing palliative care in Romania. |
| 1997 | Palliative care education programs commence in Romania. |
| 1997 | The Romanian National Association for Palliative Care is formed. |
| 1997 | Hospice Emanuel is the second service to provide palliative care in Romania. |
| 2000 | Palliative care is recognised as a medical subspecialty. |
| 2001 | Oral Morphine is made available. |
| 2002 | First Romanian palliative care inpatient unit opened by Hospice Casa Sperantei. |
| 2003 | First standards for palliative care produced and adopted by service providers. |
| 2004 | The National Commission for Palliative Care is appointed in the Ministry of Health and a draft regulation concerning palliative care services is produced (the regulation has yet to be adopted). |
| 2005 | The inpatient unit at Hospice "Sf. Irina" is officially opened. |
| 2005 | Funding for palliative care inpatient units is included in the frame contract of the House of Insurance. |
| 2005 | The National Association for Palliative Care marks the publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organisation of palliative care) by translating it and hosting an official launch. |
| 2005 | Law nr 339/Nov 2005 replaces the old (and restrictive) opioid legislation (to be enacted in 2006 following approval and publication of regulations accompanying the law). |

EAPC Palliative Care Euro-Barometer 2005

The first inpatient unit opened in a public hospital in 2007 with reimbursement for palliative care admissions. The Health Budget Monitoring costing project commenced in 2008 and home care services were acknowledged in funding schemes in 2010

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- 2005-2007 – Opioid Laws and Norms are passed.
- 2007 – First public reimbursement for palliative care admissions in inpatient units.
- 2007-2008 - Public awareness campaign and national survey.
- 2007 – First inpatient unit opens in a public hospital.
- 2007 – National coalition of palliative care providers created under the umbrella of the National Association.
- 2008 – Partnership established (to develop national strategy) between Ministry of Health (MoH), Hospice Casa Sperantei and the National Coalition of Cancer Patients Association.
- 2008 – The Health Budget Monitoring costing project commences; Hospice Casa Sperantei (in collaboration with international experts) develops frameworks for costing inpatient and home-based palliative care services.
- 2009 – Palliative care curricula in basic training for nurses is developed and implemented in all colleges of nursing. The palliative care "trainer of trainers" manual is published.
- 2010 – Home-based palliative care services are acknowledged in funding schemes.
- 2010 – The first Master's degree program in palliative care is launched (clinical aspects and management in palliative care) at Brasov Medical Faculty (in partnership with Hospice Casa Sperantei).
- 2011 – Five medical faculties in Romania introduce palliative care into basic studies curricula (as an optional or compulsory component).
- 2011 – 22 clinical protocols are developed.

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: Palliative care departments/wards have opened in public hospitals
- Nursing homes: There is no information available at this time.
- Residential homes for the elderly: There is no information available at this time.
- Other community settings: Home care services, day care services and outpatient clinics have been developed.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

- There are a few palliative care services that include patients with HIV, BPOC, heart failure, neurological problems, etc.
- There has been an increased interest in training to acquire palliative care competence amongst non-oncological specialists.

Perceived barriers to the development of hospice and palliative care:

- Lack of financial resources
- Legislation
- Human resources
- Lack of basic and post-graduate training in palliative care

Perceived opportunities for the development of hospice and palliative care:

- Regional development of palliative care
- Educational development
- Implementation of protocols

Other issues relevant to the development of hospice and palliative care:

Constant leadership has been provided by Hospice Casa Sperantei (and international partners).

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- The National Association for Palliative Care (Asociatia Nationala de Ingrijiri Palliative (ANIP)) was formed in 1998; the association has a website (www.anip.ro), and is representative of the whole country.
- The Romanian Society for Palliatology and Thanatology (Societatea Romana de Paliatologie si Tanatologie (SRPT)) was formed in 1998 and is representative of the whole country.

Directory or catalogue of palliative care services:

A printed catalogue of palliative care services in Romania was published in 2007, 2008-2009 and 2010. It has been available online since 2010: <http://www.studiipaliative.ro/pagini/catalog-serviciilor-de-ingrijiri-paliative>.

Congresses, scientific meetings or scientific journals in palliative care:

- The Conference of the National Association for Palliative Care is held annually.
- A palliative care journal is available online: paliatia.eu
- A hospice bulletin is published four times per year.

Palliative care research capacity:

There is no information available at this time.

Palliative care collaboration:

- There is collaboration between Hospice "Casa Sperantei" Brasov, Hospice "Emanuel" Oradea, and the Association for Mobile Palliative Care Services, Bucharest. These palliative care services/teams are in constant contact with other palliative care services/teams outside Romania. Hospice "Casa Sperantei" has developed several projects in South-Eastern Europe with other countries, and is widely recognised as a regional training center.
- The Association for Mobile Palliative Care Services collaborates with palliative care teams in Spain and Switzerland.
- Pioneers include: The Romanian Society for Palliatology and Thanatology. Dr Constantin Bogdan was the manager of the Chronic Diseases Hospital "Sf Luca" in Bucharest. He perceived the need for palliative care in oncological, neurological, and geriatric patients and tried to implement this new concept of care into the medical system. He is the president of the Romanian Society for Palliatology and Thanatology.
- Hospice "Casa Sperantei" was born from the initiative of an English citizen (Graham Perrolls), who raised funds for a hospice team in Brasov. He is the president of Hospice "Casa Sperantei".
- Hospice "Emanuel" Oradea, Hospice "Casa Sperantei" Brasov, and Hospice "Sf. Irina" Bucharest all organize activities (and lobbying initiatives) to celebrate World Hospice and Palliative Care Day.

Worldwide palliative care alliance level of development:

3A (Isolated palliative care provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

There have been a number of developments in palliative care education and training initiatives.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Palliative care courses for students (in the fifth/sixth year of study) have been provided in five universities
- Nursing: In 2009, palliative care curricula in basic training for nurses was introduced
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: The program of palliative care as a subspecialty is ongoing; online courses are available; there is continuous medical education involving face-to-face training programs; there is a "train the trainers" program; there are palliative care research courses available; there is a multidisciplinary Master's degree program available
- Nursing: there is continuous medical education involving face-to-face training programs; there is a "train the trainers" program; there are palliative care research courses available; there is a multidisciplinary Master's degree program available
- Social work: there is continuous education involving face-to-face postgraduate training programs; there is a "train the trainers" program; there are palliative care research courses available; there is a multidisciplinary Master's degree program available
- Other professions (psychologists, clerics): there is continuous education involving face-to-face training programs; there are palliative care research courses available; there is a multidisciplinary Master's degree program available.

Translation of palliative care documents or other materials:

Several palliative care books have been translated:

EAPC White Paper on standards and norms for hospice and palliative care in Europe;
European Association for Palliative Care - Recommended framework for the use of sedation in palliative care;
ELNEC International Curriculum;
Sheila Payne, Jane Seymour and Christine Ingleton - Palliative Care Nursing;
WHO. Cancer Control. Knowledge into Action. Palliative Care;
WHO. Cancer Control. Knowledge into Action. Policy and Advocacy;
Derek Doyle, Roger Woodruff - The IAHPC Manual of Palliative Care. 2nd Edition;
Council of Europe, Resolution 1649(2009) - Palliative care: a model for innovative health and social policies.

In 2007, the National Coalition of Palliative Care Providers was created under the umbrella of the National Association; in 2008 a partnership was established to develop national strategy between this organisation, the Ministry of Health and Hospice Casa Sperante

Initiatives to develop healthcare professional leadership in palliative care:

- There has been faculty development at the nursing colleges.
- “Training of trainers” program at five medical universities.
- “Training of trainers” program for postgraduate continuous medical education courses.
- The Master’s degree program focuses on clinical aspects and management in palliative care.
- Organizational and leadership courses for healthcare professionals in palliative care services.
- Two Romanian palliative care professionals have received training at the Leadership Development Initiative, Institute for Palliative Medicine, San Diego, USA.

Officially recognized medical certification:

Since 2000 (by an order of the Ministry of Health), all medical specialties in Romania have been accepted as initial forms of specialization for the recognition of palliative care as a sub-specialty. Training lasts 18 months, including a 12-week course (eight weeks theoretical training and four weeks clinical practice). To date, approximately 300 professionals have been accredited in this way.

Capacity of palliative care workforce training in Universities and Medical Schools:

- Romania has eleven medical schools (national data); there are an estimated two palliative care courses (compulsory component).
- As palliative care is a subspecialty (not a specialty), there is no “cathedra” of palliative care. Physicians who have achieved palliative care as a subspecialty can become trainers in palliative care (“formatori”), after completing a special course in teaching.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006**Developments/opportunities/barriers relating to the availability of essential medications:**

More opioids are now available in Romania (including oral forms); new opioids have been registered in the country.

Developments/opportunities/barriers relating to the accessibility of essential medications:

- There are still problems in prescribing and fears among the population in relation to opioids
- A new law relating to the accessibility of essential medications is due to be enacted.

Developments/opportunities/barriers relating to the affordability of essential medications:

There are National Programs for cancer patients involving a system for compensated medication, but not all opioids are covered; some opioids are only 50% compensated and for non-cancer patients there is still plenty of room for improvement.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

A new law has been passed and regulations relating to this law have been adopted. The changes brought by the new law can be found in the article: Mosoiu D, Mungiu OC, Grigore B, Landon A, Romania: Changing the regulatory environment, *Journal of pain and Symptom Management* 2007, 33, 5:610-614.

Initiatives to promote attitudinal change in relation to ‘opiophobia’:

In 2007-2008, there was a public awareness campaign and national survey in relation to this issue.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

There have been initiatives that consider access to essential medication as a legal and human right.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006**Most important legal or policy changes affecting the development of hospice and palliative care:**

- 2007 – Opioid Laws and Norms are passed .
- 2007 – First public reimbursement for palliative care admissions in inpatient units.
- 2008 – Partnership established (to develop national strategy) between Ministry of Health (MoH), Hospice Casa Sperantei and the National Coalition of Cancer Patients Association.
- 2010 – Home-based palliative care services are acknowledged in funding schemes.
- 2010 – The staffing ratio for palliative care inpatient units is approved by a Ministerial Order.
- 2010 – The national curriculum includes one semester of palliative care as a compulsory component in the training of nurses in colleges (by an Order of the Minister of Education).

The impact of these policy changes and ways in which they have been important:

- Improved access to opioid medication for patients; all doctors (including GPs) can now prescribe opioids to patients with pain.
- Increased funding for palliative care inpatient units.
- The key role of Hospice Casa Sperantei in the development of palliative care in Romania is recognized.
- Funding is provided by the Romanian government for home-based palliative care services.
- The appropriate number of staff can now be employed in providing palliative care services; the multidisciplinary team is recognised.

Development of a national palliative care consensus:

- (i) National standards and clinical protocols have been produced and are in the process of being adopted
- (ii) Draft palliative care legislation has been submitted to the Romanian parliament; it has support from the health commission in the deputy chamber.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

- There have been several meetings with MPs from different political parties to sustain the development of palliative care in Romania.
- A national conference was held at the Romanian parliament in 2010, followed by the decision of 29 MPs to initiate amendments to the health law to include palliative care.
- The 2011 international conference “Sharing and Networking” was attended by the Minister of Health following the engagement of the Ministry of Health in developing a national palliative care strategy.

Development of an advocacy framework for integrating palliative care into the health care system:

An advocacy framework has been developed for integrating palliative care into the healthcare system.

Strategies to improve political awareness and government recognition of palliative care:

- Hospices have worked in conjunction with relevant authorities to draft the following documents:
 - Amendments submitted to the Parliament for Health Law No.95/2006 regarding health services (June 2010).
 - Amendments to Ministerial Orders submitted in 2009 (authorization of service providers; staff ratio for providing palliative care in inpatient units).
- Raising public awareness through press conferences.
- The results of the costing projects and research projects relating to opportunities for developing palliative care in the public healthcare system have been widely disseminated.
- Materials have been distributed to Local Health Boards and palliative care providers.
- A draft of the National Palliative Care Strategy was developed by palliative care professionals and members of the National Coalition of Palliative Care; the strategy was submitted to the Ministry of Health in 2012.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

As above.

Involvement with the European Union in relation to hospice and palliative care initiatives:

There have been several projects involving the European Union in relation to hospice and palliative care initiatives.

Development of initiatives framing palliative care as a 'human right':

- The human rights argument has been used for promoting the legal changes relating to palliative care.
- An international conference was organized by Open Society Foundation in relation to this issue in Romania in 2011.

General legislation relating to palliative care:

There is no specific law governing the provision of palliative care services. The law 95/2006 regarding health care in Romania does not specifically refer to palliative care services. For home-based palliative care, the 2010 Frame-Contract for the provision of medical care differentiates for the first time between general home care and home-based palliative care; only teams containing a specially trained physician can deliver palliative care.

Published national documents relating to palliative care standards and norms:

Printed National Standards for Palliative Care are available (first published in 2002).

National Plan or Strategy of Palliative Care:

- In 2012 a National Strategy for Palliative Care was developed by Romanian specialists with the support of consultants from NICE (National Institute for Clinical Excellence), UK. Based on the Strategy, a National Program for Palliative Care was submitted to the Ministry of Health, including a national budgetary projection for the following years to improve coverage by setting up services and developing staff training programs. The strategy envisages development of palliative care as a basic approach (primary care) and specialized services. The program is yet to be approved by the Ministry of Health.
- However, there is a high turnover in relation to the Ministers of Health (22 since 1989), which makes it difficult to ensure continuity of strategy in palliative care (especially when public funds are scarce). Several Ministers of Health have recently declared that palliative care is an area where a strategy is required; particularly in relation to accessing palliative care services and opioid availability.

National Cancer Control Strategy:

There is a National Cancer Control Strategy with an explicit reference to palliative care (but there is no financial support for this plan). There are no protected funds for symptom control (morphine), which results in a situation where all opioids required by cancer patients (for chemotherapy and supportive and palliative care) are in competition for the same funding from the national budget.

National HIV/AIDS Strategy:

The National HIV/AIDS Strategy (2011-2015) is still awaiting approval from the Romanian government. It contains an acknowledgement that HIV/AIDS patients may require palliative care and there is a plan for developing five inpatient units to provide this form of care (not just for HIV/AIDS patients).

National Primary Health Care Strategy:

There is a National Primary Health Care Strategy but it does not contain a reference to the provision of palliative care.

Designated policy maker for the delivery of palliative care services:

The Ministry of Health has an oncology committee which is responsible for decisions to be taken in the field of oncology. The oncology committee has a "palliative care subcommittee" (consisting of three people), which is responsible for the development of palliative care policy.

Department of Health specific responsibility for the delivery of palliative care services:

The Ministry of Health authorizes specific structures (teams, departments) to provide palliative care services. These structures may choose to have a contractual relationship with the National Health Insurance System (for reimbursement of costs) if they wish.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- Every physician has the legal right to prescribe strong opioids, but this must be done on a special yellow form. General practitioners cannot prescribe strong opioids free of charge if there is no specialist indication (almost all indications are from oncologists). By law, strong opioids should be available in each pharmacy that employs a pharmacist (including hospitals). But there is a lack of strong opioids in pharmacies and patients and families have to make great effort to obtain the prescribed drug (telephone calls to each pharmacy, visiting all pharmacies near/far from their home, etc.)
- Several books have been published about cancer pain and its treatment, including manuals of palliative care (original or translated editions); however, they are not widely available (they are printed mainly in small numbers, in regional editions with restricted availability).

Funding of palliative care services:

- The National House of Health Insurances cover the costs of palliative care services (public or private) provided in inpatient units (as costs per admitted patient per day, up to a limited amount) and of home-based palliative care by costs per visit. Services initially provided by charitable organizations are currently developing in the public health system. Palliative care services are also available on a private basis (by patients' direct payment).
- Partial payment may be required for palliative care consultation and hospitalisation.
- Partial payment may be required for palliative care medications. There are a number of opioids that patients can get free of charge (there is a list of drugs revised periodically by the Ministry of Health). In cases where a number of different opioids are required, only the cheapest product in the category is received free of charge. Each medical specialty has a list of opioids that can be received free of charge (but this is not a list of palliative care opioids available to all patients); for example, some strong opioids are only free of charge for cancer patients.

In 2012 a National Strategy for Palliative Care was developed by Romanian specialists with the support of consultants from NICE (National Institute for Clinical Excellence), UK

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:
In 2007-2008, a public awareness campaign and national survey were undertaken.

Major public discussion, debate or controversy about hospice and palliative care:

There is no information available at this time.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

There have been a variety of media campaigns to broaden awareness and understanding of hospice and palliative care.

Hospice or palliative care 'success' stories:

There have been a number of hospice/palliative care 'success' stories in Romania. An example is the costing project developed by Hospice Casa Sperantei with support of OSF funding, to evaluate costs of palliative care in inpatient units and in home-based care and to establish a costing frame and actual costs based on agreed standards. The results presented to the National House of Health Insurances lead to setting the base for a new mechanisms for funding home-based care and for a more realistic reimbursement mechanism for inpatient services. The project was also successfully replicated in the Republic of Moldova.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is no information available at this time.

In 2009, a palliative care curriculum was introduced for nurses. The first Master's degree program in palliative care was launched in 2010, and five medical faculties introduced palliative care into basic studies curricula in 2011

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

It is hoped that there will be increasing development in palliative care.

Most significant issues facing hospice and palliative care in the next three years:

- The National Palliative Care Strategy (which contains both short and medium-term implementation plans) and appropriate allocation of funds.
- Several palliative care services are currently under construction (hospices, inpatient departments).
- Maintaining standards of quality concomitant with increasing the number of palliative care services
- Extending basic and post-basic medical and nursing training to cover the development of services at a national level.

Implications for palliative care relating to the current economic crisis:

- There is a drain on financial and human resources caused by many trained healthcare professionals leaving the country.
- Insufficient funding allocated for palliative care (in particular for home-based care).

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Russia¹

NATIONAL ASSOCIATION/KEY CONTACT

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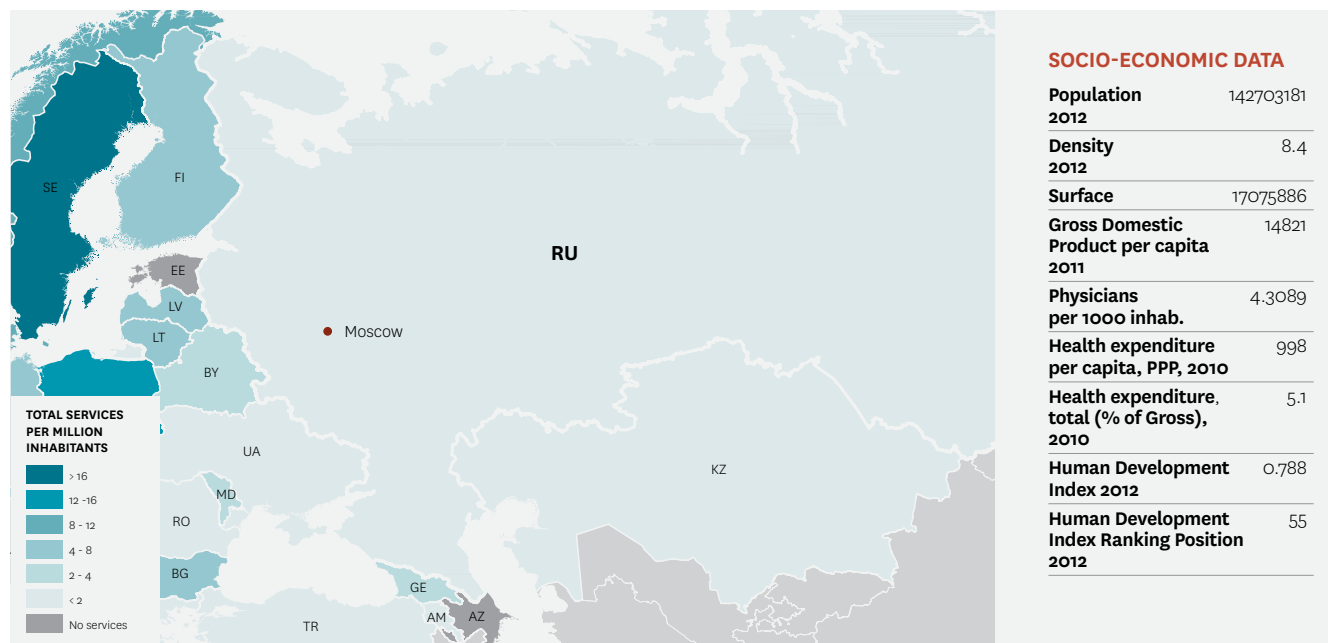
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | ○ |
| Hospital palliative care support team | ○ |
| Home palliative care support team | ○ |
| Mixed palliative care support team | ○ |
| Palliative care units in tertiary hospitals | 9 (175) |
| Palliative care units in non-tertiary hospitals | 30 (789) |
| Inpatient hospice | 23 (799) |
| Day hospice/day care centre | ○ |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Personal estimates/estimates provided by experts
- Olga Usenko
- Charity Foundation "Vera", Russia, website: www.hospicefund.ru
- Herten Cancer Research Institute: www.mnioi.ru

Additional comments:

New palliative care services for children have been established (and more are due to be opened) and palliative care units for HIV/AIDS patients have been developed.

Palliative care services for children:

There are two paediatric home palliative care support teams and 6 paediatric inpatient units (38 beds+).

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|------------------|--|
| 1990 | The first hospice opens in St. Petersburg. |
| 1995-97 | Through the advocating of hospices, the federal regulations on strong opioids are increased to acceptable levels. |
| 2001-2002 | In several regions of Russia, non-injectable forms of opioids are officially adopted into palliative care practice (an initiative of the palliative care association and palliative care practitioners). |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- Palliative care has been approved as a separate type of medical care alongside primary medical care, emergency medical aid and specialised medical care by the new Federal Bill on Health in Russia (2011).
- Federal palliative care guidelines for adults and children (including people living with HIV) have been developed by the Health Ministry and will be approved in 2012.
- The Health Ministry plans to establish a “reasonable amount” of palliative care units in every region of the country.
- A palliative care department in Moscow plans to commence a Certificate in Palliative Care Education for doctors and in a number of other cities similar palliative care courses will be established (this information was presented by the official Health Ministry representative at a palliative care conference in Moscow in June 2012).
- The community is increasingly informed about hospice and palliative care and is interested in its development.

Overall progress in hospice and palliative care:

There has been some progress in hospice and palliative care.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: has remained the same
- Nursing homes: has remained the same
- Residential homes for the elderly: has remained the same
- Other community settings: has remained the same

Expansion from a focus on cancer patients to address the needs of ‘non-cancer’ patients:

Palliative care has been expanded to include patients with HIV/AIDS, heart failure and lung failure (the new National Handbook for Cardiologists contains a chapter on palliative care).

Perceived barriers to the development of hospice and palliative care:

- Lack of suitably qualified staff.
- Lack of funding.
- Lack of palliative care education/training opportunities and interest within the medical community.
- Despite the fact that more than two million people die every year in Russia (about 300,000 patients from cancer and more than 14,000 patients from HIV/AIDS), there are only approximately 62 hospices and palliative care units in the country.
- Many hospices and palliative care services are located in unsuitable buildings.
- The amount of opioids provided is minimal and does not satisfy the requirements of the World Health Organization (WHO).

- The number of staff providing palliative care services does not comply with the recommendations of the European Association for Palliative Care.
- Logistical support and funding are unsatisfactory.
- Wages for health professionals engaged in palliative and hospice care are extremely low in some regions.
- Guidelines for pain management do not always meet WHO recommendations.
- Standards for palliative care are under development.
- There is no quality control process to assess the effectiveness of the palliative care provided
- The system of ordering opioids for patients (who have the right to receive a variety of social services) is restrictive (but has improved recently). The existence of subsidized prescriptions does not correspond to the commitments promised by the Government of the Russian Federation. The benefits provided by Federal Law No. 122 of 2004 for patients with a disability (based upon the fact that they have cancer), are much lower than the price of medicines included in the List of Essential Medications that is created by the Ministry of Health and Social Development of the Russian Federation.
- The approved Lists do not contain effective modern medicines for pain management such as oral morphine, transdermal systems of fentanyl, and medicines necessary for palliative chemotherapy.
- Requests for additional pharmacological support are created not by the treating physician, but by the Chief Physicians (Chief Executive Officers) of polyclinics who are influenced by the limited amount of funds available. The procedure for prescribing opioids and other strong medications is complicated and time-consuming.
- A prescription for a patient can only be written inside a polyclinic by the treating physician, who has special approval to administer strong opioids, in spite of the fact that a non-transportable patient should first be examined by a doctor at their home;
- Authorization to administer opioids is granted by the Senior Physician of the Division or the Chief Physician of the polyclinic, who are not involved in the patient’s treatment. This procedure is contrary to international standards of treatment and care;
- A patient or the patient’s relatives can only obtain opioids from a certain pharmacy, and there may be limitations to the number of eligible pharmacies in a certain city or district;
- There are limits for administering opioids in a prescription, as well as maximum daily doses, which do not comply with WHO recommendations. In addition, prescriptions for opioids are valid for only ten days from the date of issue.
- Doctors may face administrative pressures when they demand permission to order up-to-date or modern medicines for the management of severe pain for patients in adequate amounts;
- As a result, medicines that doctors often prescribe for the treatment of chronic pain are tramadol, injectable morphine, and promedol. The most common prescription includes ten ampoules of injectable morphine or promedol. The treating physician cannot prescribe even a single packet of 20 tablets of time-released opioid (MST-Continus) or five patches of transdermal fentanyl. Even though a patient has clinical indications for an opioid prescription, sometimes doctors refuse to prescribe them due to a lack of opioids at the pharmacy or because of quantitative restrictions on prescriptions.
- In dealing with the treatment of the terminally ill in hospital, there may be problems with providing injectable opioids in adequate doses, because of low existing standards of opioids per bed per year.

Palliative care was approved as a ‘separate type’ of medical care alongside primary medical care, emergency medical aid and specialised medical care by the new Federal Bill on Health in Russia (2011)

- In the Russian Healthcare System, Palliative Medicine for physicians and Palliative Care for nurses are not listed as approved specialties (although it should be acknowledged that Russia is not alone in this regard and is in a similar position to many other European countries). Postgraduate education in this area is conducted only for a small number of specialists. Certification for personnel and assessment of competence in palliative medicine and palliative care are not conducted. Methodological work in this field is poorly organized.
- In conclusion, the majority of dying patients in the Russian Federation do not have access to palliative care. The recommendations of WHO for pain management are being violated. The majority of patients do not receive adequate doses of modern and effective opioids (if they receive any at all). Medical students and medical professionals are not educated in palliative care for the terminally ill. Control of opioids is convenient for health care administrators, but contradicts the interests of patients. Doctors who are faithful to their professional oath are oppressed by their local administrations and institutions.

Perceived opportunities for the development of hospice and palliative care:

- Outline clearly stated primary approaches for the integration of palliative care into the existing Russian healthcare system (the process of integration has commenced with the inclusion of palliative care as a type of medical care by the Federal Law).
- Create laws and regulations that require the education of undergraduate medical and nursing students and postgraduate physicians, nurses, and social workers in the most modern principles of palliative care and effective pain management;
- Guarantee that essential palliative care medicines such as strong opioids (especially immediate release oral morphine), are available in sufficient quantities for effective pain management for all terminally-ill patients.

Other issues relevant to the development of hospice and palliative care:

There is no information available at this time.

Palliative care research capacity:

- Palliative care research capacity exists within different clinical fields (mostly in cancer clinics in different cities)
- Researchers include: Abuzarova Guzel (abuzarova_mnioi@bk.ru), Berezhkov Valery (berezhkovval@mail.ru), Berezhkova Olga (berezhkova59@mail.ru), Bialik Marina (marina.bialik@gmail.com), Ekkert Natalia, Larionova Oksana (oka-loka@mail.ru), Ryabova Lilia (L57505@yandex.ru), Sharafutdinov Marat (msharafutdinov@ravnoepravo.ru), Usenko Olga (olga_usenko@yahoo.com), and Vedernikova Valeria (valery.gv@mail.ru).

Palliative care collaboration:

- Collaborations include: Professor Jacek Luczak, President, Eastern and Central Europe Palliative Care Task Force; Diederik Lohman, Senior Researcher, Human Rights Watch; (HRW) and Anna Sevortian, Director, Russia Office, HRW.
- Pioneers include: Hospices in St. Petersburg; First Moscow Hospice; Kemerovo Regional Hospice and palliative care departments; Ulyanovsk Regional Hospice; Palliative Care Center at the Herten Cancer Research Institute; Moscow Medical University.
- Collaboration exists within the country – through conferences, annual seminars in Moscow, and through websites (www.pallcare.ru and www.hospice.ru).
- A number of Russian specialists are the members of international organisations such as the European Association for Palliative Care (EAPC) and the International Association for the Study of Pain (IASP) – some Russian specialists provide lectures for international students within IASP activities.
- There is strong collaboration within paediatric palliative care – for example, with the International Children's Palliative Care Network (ICPCN) which contains Russian members – and the board of the Eastern European Paediatric Palliative Care Association led by Anna Gorchakova (Belarus).
- World Hospice and Palliative Care Day is acknowledged in Russia (website: www.hospiceday.ru).

Worldwide palliative care alliance level of development:

3A (Isolated palliative care provision).

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- The Russian Association for Palliative Medicine (Российская ассоциация паллиативной медицины) was formed in 2012.
- There is an Inter-regional Hospice Association in St Petersburg.
- A National Hospice Association is being developed in Moscow.

Directory or catalogue of palliative care services:

- A catalogue of palliative care services is available online: Charity Foundation "Vera", Russia, website: www.hospicefund.ru
- Since 2006, hospice and palliative care resources and information have been available on the website: www.pallcare.ru

Congresses, scientific meetings or scientific journals in palliative care:

- There are National Congress and Regional Conferences held annually in different cities and attended by approximately 100-300 participants.
- The journal Palliative Medicine and Rehabilitation has been published since 1996 (four times per year).
- Other journals that have published palliative care articles relating to Russia include: Clinical oncology, Oncology, Haematology, Advances of Gerontology, Clinical Gerontology, Issues of Social hygiene, History of Medicine, Attending Physician (and many others).
- The number of medical specialists attending international congresses and events has grown (reference EAPC reports).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

There is no information available at this time.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: No developments.
- Nursing: No developments.
- Social work: No developments.
- Other professions: No developments.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: There is one chair in Palliative Medicine
- Nursing: There is one chair in Palliative Medicine and four or five courses in Palliative Medicine
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Translation of palliative care documents or other materials:

There has been some translation of palliative care documents and other materials (EAPC White paper on standards and norms; Morphine manifesto; EAPC e-newsletter; some articles and guidelines in paediatric palliative care).

Initiatives to develop healthcare professional leadership in palliative care:

There is no information available at this time.

Officially recognized medical certification:

- Postgraduate courses for physicians include 144 hours of clinical training (over 1500 physicians have been trained since 1999).
- Postgraduate courses for nurses include 72 hours of clinical training.
- Palliative care is also taught to medical students within the courses of oncology, medical ethics, cardiology, neurology, and HIV/AIDS.

Capacity of palliative care workforce training in Universities and Medical Schools:

- Russia has 88 medical schools. It is estimated that Palliative Medicine is available as an optional component at five: two in Moscow; one in St Petersburg; one in Ulyanovsk; and one in Ufa.
- Commencing in 2013, palliative care education will be obligatory for all medical staff working in palliative care units (as stipulated in the Bill on Health).
- It is estimated that there is one full Professor in Palliative Medicine, two assistant professors, and one "other professor" (based on personal experience).

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006**Developments/opportunities/barriers relating to the availability of essential medications:**

There is no information available at this time.

Developments/opportunities/barriers relating to the accessibility of essential medications:

There is no information available at this time.

Developments/opportunities/barriers relating to the affordability of essential medications:

There is no information available at this time.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

Regulations are very strict although there have been some essential changes to the law since 2007.

Initiatives to promote attitudinal change in relation to 'opiophobia':

There is no information available at this time.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

Federal palliative care guidelines for adults and children (including people living with HIV/AIDS) were developed by the Ministry of Health. The community is increasingly informed about hospice and palliative care and is interested in its development

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006**Most important legal or policy changes affecting the development of hospice and palliative care:**

Currently the Ministry of Health of the Russian Federation is working on a policy for palliative care provision for adults and children (preliminary guidelines have been already developed).

The impact of these policy changes and ways in which they have been important:

There is no information available at this time.

Development of a national palliative care consensus:

There is no information available at this time.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

In 2012, a special Taskforce on pain control and opioid availability was formed by the Ministry of Health.

Development of an advocacy framework for integrating palliative care into the health care system:

There has only been fragmented work in this area.

Strategies to improve political awareness and government recognition of palliative care:

There have been no such strategies.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

- The first children's hospice has been built by the government (building of the second children's hospice has commenced in Moscow). These hospices were established through support provided by the charities (MOSCOW and KASAN).
- Several palliative care units have been established in different regions of Russia funded by the local government.
- Several respected NGOs in Russia support the development of palliative care in the country (including paediatric palliative care).

Involvement with the European Union in relation to hospice and palliative care initiatives:

There is no information available at this time.

Development of initiatives framing palliative care as a 'human right':

- All-Russian campaign "Difficult Conversation".
- There have been some initiatives by the advocates for paediatric palliative care and by the Foundations supporting palliative care in Russia.

General legislation relating to palliative care:

- Two fundamental laws exist in relation to palliative care provision for cancer and HIV/AIDS patients.
- General legislation is in process: currently the Ministry of Health is working on a law which will approve the guidelines and norms relating to the provision of palliative care.

Published national documents relating to palliative care standards and norms:

Palliative care standards are in process: currently the Ministry of Health is working on developing palliative care standards.

National Plan or Strategy of Palliative Care:

There is no information available at this time.

National Cancer Control Strategy:

- A National Cancer Control Program exists in Russia: Order #944N from the Ministry of Health and Social Development of the Russian Federation (December 3, 2009) regulates palliative care for cancer patients.
- The National Cancer Control Program is being implemented in most regions; it is funded by the government and includes extensive modernisation to cancer centres.

National HIV/AIDS Strategy:

Order #610 (September 17, 2007) from the Ministry of Health and Social Development of the Russian Federation regulates palliative care for patients with HIV/AIDS. The Order contains a special chapter relating to palliative care.

National Primary Health Care Strategy:

There is a National Primary Health Care Order (issued in 2012) that contains a chapter on primary medical care (including the provision of palliative care for patients both in the polyclinic and at home).

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

There is no information available at this time.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- For terminally-ill cancer patients, opioids for chronic pain can be prescribed by the attending physician after a recommendation from an oncologist and the resolution of the Physician Commission. If an oncologist is not available, the resolution from the Physician Commission authorizes the attending physician to prescribe opioids.
Source: Order #110 (2007) from the Ministry of Health and Social Development of the Russian Federation.
- There are printed pain guidelines: Order #110 of the Ministry of Health and Social Development of the Russian Federation (February 12, 2007); "Clinical recommendation in pain management", Ministry of Health and Social Development of the Russian Federation, 2011. Online version: http://www.sartfoms.ru/llo/110_12_02_07.htm; <http://paininfo.ru/articles/4301.html>

Funding of palliative care services:

- There is no payment required for palliative care consultation or hospitalisation.
- Opioids are free of charge for terminally-ill cancer patients with verified diagnoses.
- There are a number of respected charitable foundations (including those for children).
- Funds for development have been provided by Charity Foundation "Vera".

A palliative care department in Moscow plans to commence a Certificate in Palliative Care for doctors; similar palliative care courses are due to be established in a number of other Russian cities

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

Hospice and palliative care are being actively discussed in the mass media, on TV, and on the internet – several movies have recently been made by journalists (over the past three years).

Major public discussion, debate or controversy about hospice and palliative care:

There has been public discussion about hospice and palliative care.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

There have been initiatives that seek to broaden awareness and understanding of hospice and palliative care.

Hospice or palliative care 'success' stories:

- The First Moscow hospice.
- Hospice and palliative care services in St Petersburg (including the first children's hospice).

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is no information available at this time.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

Some limited progress has been made in the development of hospice and palliative care in the Russian Federation; further progress is possible due to the official inclusion of palliative care into the government health system (Federal Bill on Health, 2011).

Most significant issues facing hospice and palliative care in the next three years:

There is no information available at this time.

Implications for palliative care relating to the current economic crisis:

There is no information available at this time.

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Serbia¹

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | ○ |
| Hospital palliative care support team | 1 |
| Home palliative care support team | 1 |
| Mixed palliative care support team | ○ |
| Palliative care units in tertiary hospitals | ○ |
| Palliative care units in non-tertiary hospitals | ○ |
| Inpatient hospice | ○ |
| Day hospice/day care centre | ○ |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

All data based on personal estimates.

Additional comments:

- The hospital palliative care support team is based at the Institute of Oncology and Radiology in Serbia. This is staffed by one physician with limited palliative care experience (not specialist physician training).
- There is one home palliative care support team in Serbia; it is the NGO BEL-hospice. This team consists of two doctors, one of whom is not a specialist as such (because there is no palliative care specialist certification in Serbia) but she has extensive practical experience working under a specialist palliative care physician. The other doctor is relatively new to palliative care. There are two nurses affiliated with the team.
- There are no existing palliative care units in non-tertiary hospitals. The Ministry of Health is in the process of developing such units, although they will not be staffed with palliative care specialists but rather by doctors and nurses with limited experience in palliative care. It is possible that some of these units will open in 2012.

Palliative care services for children:

There is no information available at this time.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|--------|---|
| 1994 | Regulations on the prescription of morphine (previously limited to only 200 mg per prescription) are changed to allow doctors to prescribe the amount necessary for two weeks of treatment. |
| 1996 | The first service for cancer pain management (providing consultations for inpatients as well as for outpatients) starts at the Institute for Oncology and Radiology of Serbia (head: Dr Snezana Bosnjak). |
| 1996 | Useful local publications are produced such as a "user friendly" handbook for physicians and nurses on the pharmacotherapy of cancer pain, together with an educational flyer: "True and false about the use of oral morphine in cancer pain management" (Dr S Bosnjak, Dr S Radulovic). |
| 1996 | The Institute for Oncology and Radiology of Serbia translates the WHO monograph on cancer pain relief (Dr S Radulovic, Dr S. Bosnjak). |
| 2000 | The Institute for Oncology and Radiology of Serbia translates the WHO monograph on symptom relief in terminal illness (Dr S Radulovic, Dr S. Bosnjak). |
| 2003-5 | Several international and national courses devoted to palliative care and supportive cancer care are organized. For example: Palliative Care School (October 2004: 35 participants; May 2005: 35 participants); an International Education Symposium on Supportive Care in Cancer Patients (under the auspices of the Serbian Medical Association and Multinational Association of Supportive Care in Cancer (MASCC) October, 2004: 158 participants); two courses held on palliative care in patients with lung cancer (April, 2002: 140 participants; December 2004: 200 participants) and two courses on palliative care for elderly patients (October 2003: 90 participants; March 2005: 128 participants). |
| 2004 | The first NGO devoted to palliative care (Center for Palliative Care and Palliative Medicine, BELhospice) is established (director: Dr Nataša Milicevic), as a non-profit organisation with the goal to promote palliative care as a discipline, to provide good quality palliative care for patients and their families, to organize education in the palliative care field and to promote the idea and the philosophy of hospice/palliative care in the country. BELhospice is supported by Hospice of Hope from the UK as part of the "Beacon Project". |
| 2004 | The first postgraduate Diploma in Palliative Medicine is established. |
| 2004 | The Center for Palliative Care and Palliative Medicine, BELhospice translates the Council of Europe (2003) Recommendations of the Committee of Ministers to member states on the organization of palliative care (Dr Nataša Milicevic). |
| 2004 | The first national Palliative Care Guidelines for the management of cancer pain, dyspnoea and nausea are prepared and published. |

(…)

(…)

2005

The 'National Task Force for Palliative Care' is established under the auspices of the Ministry of Health (president: Dr Nataša Milicevic, Vice-President: Dr Snežana Bošnjak). It aims to: promote palliative care goals and achievements according to the Recommendation of the Council of Europe; make palliative care an integral part of the health care system; increase awareness and knowledge about palliative care among healthcare professionals/ public; and highlight the right of patients and their families facing life-threatening illness to have the best possible quality of life. The Task Force has 15 members; among them two representatives of the Ministry of Health (public health specialists), one representative of the Ministry of Labour, Employment and Social Policy, one specialist in neurology, one specialist in infectious diseases, two specialists in internal medicine, one specialist in internal medicine (gerontology), one specialist in internal medicine (medical oncology), one general practitioner, one general practitioner (gerontology), two nurses, one psychologist and one chaplain.

2005

The National Palliative Care guidelines are disseminated and implemented.

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- Palliative care became a more interesting topic among healthcare professionals. There were some courses and many presentations on palliative care topics (mostly on symptom control).
- The European Conference on Palliative Care took place in Belgrade in 2005. It was organised by the Council of Europe (CoE) and the Serbian Ministry of Health (MoH). Approximately 300 participants from 30 countries were in attendance. The conference provided a good opportunity for Serbian policy makers to learn more about palliative care. Following the conference, a Strategy for Palliative Care was produced (adopted by the Serbian government in March 2009). The Strategy for Palliative Care is part of the wider strategy "Serbia against cancer".

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has remained the same.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: Several hospitals have started pain clinics, but holistic palliative care has yet to be introduced.
- Nursing homes: Such institutions do not exist in Serbia.
- Residential homes for the elderly: Palliative care has not been developed in this setting.
- Other community settings: There is a well-developed network of home-based care services throughout the country but these services are extended hospital services and therefore do not provide holistic palliative care. Only BELhospice is a community-based specialist palliative care service.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

There is no information available at this time.

Perceived barriers to the development of hospice and palliative care:

- There is misunderstanding about the definition of palliative care among healthcare professionals, policy makers and lay people
- There is poor education and training in the field of palliative care
- There is poor legislation regarding opioid prescribing, involvement of NGOs, etc.

Perceived opportunities for the development of hospice and palliative care:

- There is a well-developed network of home-based palliative care services.
- The European Union (EU) funded project "Development of Palliative Care Services in the Republic of Serbia" (2011-2014).
- Recently, a new law on public-private partnership has been adopted in Serbia. It presents the opportunity for NGOs to develop sustainable palliative care services.

Other issues relevant to the development of hospice and palliative care:

- BELhospice has made some impact in the development of hospice and palliative care.
- BELhospice has provided holistic palliative care for patients and their families since 2004, and held educational courses on palliative care.

Vitality

THE VITALITY OF PALLIATIVE CARE**National Associations of Palliative Care:**

Formation of a National Association of Palliative Care is in progress. There is a National Palliative Care Committee that is a task force commissioned by the government to address issues related to palliative care.

Directory or catalogue of palliative care services:

There is no information available at this time.

Congresses, scientific meetings or scientific journals in palliative care:

There is no information available at this time.

Palliative care research capacity:

There is no information available at this time.

Palliative care collaboration:

- BELhospice in Belgrade is a pioneer in the development of palliative care in Serbia.
- BELhospice has celebrated World Hospice and Palliative Care Day with many media presentations.

Worldwide palliative care alliance level of development:

3A (Isolated palliative care provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006**General developments in palliative care education and training initiatives:**

- BELhospice commenced palliative care education in October 2004. Since then, annual multi-professional courses have been held and many alumni club meetings with topics related to palliative care have occurred.
- There have been many other meetings and presentations on different occasions examining topics related to palliative care.
- In 2010, the MoH funded courses on palliative care for some professionals employed at the primary healthcare level.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: There is no information available at this time.
- Nursing: There is no information available at this time.
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: Two hours education on pain management was introduced into the curricula for postgraduate students during their GP training.
- Nursing: Several nursing schools have introduced modules on palliative care (the teachers were not previously educated in palliative care).
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Translation of palliative care documents or other materials:

The WHO guidelines "Achieving Balance in National Opioid Control Policy" have been translated into Serbian.

Initiatives to develop healthcare professional leadership in palliative care:

There have been no local initiatives for faculty development or fellowship programmes. However, one doctor has received an international grant from the Pain and Policy Studies Group (Wisconsin, USA) to improve opioid availability.

Officially recognized medical certification:

There is no officially recognized medical certification.

Capacity of palliative care workforce training in Universities and Medical Schools:

- Serbia has four medical schools but none of them have palliative care as a mandatory component of their curriculum. Undergraduates at one medical school have access to lectures on pain and symptom management as part of existing modules in the curriculum.
- There is one diploma-certified teacher of palliative medicine in Serbia (Dr Natasa Milicevic) but she is not accredited as an academic Professor of Palliative Medicine. Dr. Leonida Mirilo at BELhospice participates in palliative care education at the BELhospice School of Education (but this is not an academic appointment). Dr. Snezana Bosnjak delivers a limited number of lectures on symptom management to undergraduate medical students at the Institute for Oncology and Radiology.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006**Developments/opportunities/barriers relating to the availability of essential medications:**

- Immediate-release oral morphine is now available in Serbia, but slow-release morphine is no longer available in the country.
- Slow-release hydromorphone is available (but Codeine is not available).
- A list of essential medicines for palliative care was produced by the National Palliative Care Committee together with the strategy and action plan for palliative care development. The list follows the model of the International Association of Hospice and Palliative Care (IAHPC) but has some minor changes to reflect the reality of the situation in Serbia.
- Despite the fact that a list of essential medicines for palliative care has been produced as part of the strategy and action plan, it has not been adopted as such (although it is expected that the list will be adopted soon).

Developments/opportunities/barriers relating to the accessibility of essential medications:

The accessibility of essential medications has not improved much in Serbia.

- Although Methadone is available in the country, it is not registered as an opioid analgesic, but rather for use in substitution therapy.

- Although Haloperidol is available in the country, it is not registered as an anti-emetic but rather for use in the treatment of agitated patients.
- Many essential medications must be recommended by a specific physician (such as a psychiatrist); therefore, GPs (who usually deal with patients who require palliative care) are unable to prescribe the necessary opioids.
- The National Palliative Care Committee have made a number of recommendations for improving opioid accessibility:
 - According to new regulations, hospital doctors are not allowed to prescribe any opioid; they can only advise GPs about which opioid to prescribe. GPs are not allowed to prescribe opioids independently, but must have an official recommendation from a hospital doctor who usually does not see palliative care patients. Doctors employed by NGOs are not allowed to prescribe opioids at all and can only advise GPs; it is the GPs decision whether they accept the advice. Private doctors can prescribe all opioids but patients have to pay for the prescription.
 - This policy results in a situation where in many cases doctors must recommend opioids without seeing the patient. Doctors who are well-educated about how to prescribe opioids (and may even have educated other doctors how to do so) are not allowed to prescribe, whilst doctors who do not know how to prescribe must do so. This issue (and existing opiophobia among healthcare professionals and patients and their families) presents a considerable barrier to improving the accessibility of essential medications in Serbia.

Developments/opportunities/barriers relating to the affordability of essential medications:

There are some opioids which are available but are not affordable for palliative care patients (for example, Octreotide).

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There have been several meetings with managers of health insurance companies and doctors from BELhospice have tried to resolve this issue (but existing legislation in this area remains a barrier).

Initiatives to promote attitudinal change in relation to 'opiophobia':

Many presentations on this topic have been delivered to healthcare professionals and lay people (but it still presents a great challenge).

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

Policy makers have declared that access to essential medication is a legal and human right (but there have been no specific initiatives undertaken to change the situation).

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- The Strategy for Palliative Care and Action Plan
- The Law on psychoactive controlled substances

The impact of these policy changes and ways in which they have been important:

The Strategy was an important document which provided Serbia with an opportunity to apply for European Union funding for the development of palliative care.

Development of a national palliative care consensus:

- To date, little has been achieved in this area.
- The EU-funded project "Development of Palliative Care Services in the Republic of Serbia" (2011-2014) has several important aims: educate (through Continuous Medical Education (CME)) approximately 1500 healthcare professionals who will provide general or specialist palliative care to patients/families at all three levels of health care; develop palliative care undergraduate curricula for medical and nursing schools; establish and support future palliative care units throughout Serbia; produce palliative care standards and guidelines; recommend changes in national legislation which will allow charities to provide palliative care and sustainable services to be developed; improve prescribing policy and provide better accessibility to opioids and other essential medications for palliative care; increase public awareness regarding palliative care opportunities and possibilities.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

The National Palliative Care Committee has had meetings with stakeholders and policy makers to develop palliative care strategies. Since the Strategy for Palliative Care was completed and adopted, there have not been any significant meetings.

Development of an advocacy framework for integrating palliative care into the health care system:

Apart from development of the Strategy for Palliative Care (which is an important advocacy tool), other national advocacy frameworks have not been developed. The NGO BELhospice has developed regular public awareness-raising activities, such as media presentations, fundraising events and celebrating World Hospice and Palliative Care Day.

Strategies to improve political awareness and government recognition of palliative care:

The UK charity Hospices of Hope (a strategic partner to BELhospice), organised a visit to Serbia for some British palliative care physicians and former politicians in order to meet with healthcare policy makers and explain the advantages of well-organised palliative care within the country (and also the advantages of a public/private partnership).

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

Pain clinics working within public healthcare institutions are funded by national health insurance. The NGO BELhospice has been supported by Hospices of Hope, but relies on donations, income from fundraising activities and funds from local and international projects.

Involvement with the European Union in relation to hospice and palliative care initiatives:

The European Union currently funds the project "Development of Palliative Care Services in the Republic of Serbia" (2011-2014).

Development of initiatives framing palliative care as a 'human right':

There were some interviews with patients and their families regarding pain relief and palliative care as basic human rights (but they had limited impact).

General legislation relating to palliative care:

There is no information available at this time.

Published national documents relating to palliative care standards and norms:

There is no information available at this time.

National Plan or Strategy of Palliative Care:

The National Strategy of Palliative Care was adopted by the Serbian parliament in 2009; it was produced by the National Palliative Care Committee

National Cancer Control Strategy:

A National Cancer Control Program exists, but does not contain a specific reference to palliative care provision.

National HIV/AIDS Strategy:

A National HIV/AIDS strategy exists, but does not contain a specific reference to palliative care provision.

National Primary Health Care Strategy:

There is no information available at this time.

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

The Department of Health does not have specific responsibility for delivering palliative care services.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- There is a standard process for the prescription and acquisition of strong opioids.
- Printed guidelines have been published for the management of pain, nausea/vomiting, and Dyspnoea. They are available online on BELhospice website <http://www.belhospice.org/index.html>

Funding of palliative care services:

- There is no payment required for palliative care consultation or hospitalization; any services obtained through the public healthcare delivery system are free of charge. There are private hospitals and clinics that exist as fee-for-service facilities, so any form of care received there (palliative care or otherwise) would require payment.
- Some palliative care medications are available free of charge through the public healthcare service, but some medicines used in palliative care are not covered when used specifically for symptom management rather than disease-specific applications.
- Based on an anecdotal report, "informal payments", are accepted and at times expected to be made in order to expedite the delivery of services in the public sector (the amounts or frequency involved cannot be estimated); public-system patients are sometimes referred to the clinician's private clinic for "better services".
- Diagnosis Related Groups (DRG's) are being incorporated into the health care system; therefore, payment for medical care is essentially becoming more "disease-specific".
- The European Union (EU)-funded joint project involving the EU and the Ministry of Health "Development of Palliative Care Services in the Republic of Serbia" (2011-2014) is a 2.7 million Euro project to assist in the development of palliative care services in Serbia. In addition, the Ministry of Health has allocated 600,000 Euros towards the refurbishment of premises in Serbia to enable them to become palliative care units.

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006**Change in public awareness or perception of hospice and palliative care:**

There has been very little change in public awareness or perception of hospice and palliative care in Serbia.

Major public discussion, debate or controversy about hospice and palliative care:

There is no information available at this time.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

There have been some such initiatives (but without great impact).

Hospice or palliative care 'success' stories:

The NGO BELhospice has been providing hospice care for patients and their families free of charge and without any governmental support since 2004.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is no information available at this time.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT**The future of hospice and palliative care development:**

- According to the Strategy for Palliative Care development and its Action Plan, each municipality in Serbia with more than 25,000 inhabitants should have a home-based palliative care team. There should be at least 88 such teams throughout Serbia; 28 general hospitals should establish palliative care units by the end of 2015, and all tertiary health care institutions should have at least one specialist palliative care team. All the professionals working in this field should have at least basic education regarding palliative care and those working in palliative care units and tertiary institutions should have more extensive education and training.
- The EU-funded project "Development of Palliative Care Services in the Republic of Serbia" (2011-2014) will provide education in this area but it is uncertain whether the Serbian government will have money to pay healthcare professionals or if the Ministry of Health will have enough money to establish and equip the palliative care units.
- A genuine danger may be that public palliative care units will simply be viewed as a place for dying and not for the provision of hospice/palliative care and that professionals either in primary home care teams or those employed in palliative care units (if the units are established) will not be able to provide holistic care but will revert back to a curative model of care.
- For this reason, independent hospices that follow the principles and philosophy of holistic palliative care or a partnership between public and NGOs might be better solutions for the development of palliative care in Serbia.
- Serbia, as a country with healthcare expenditure of 270 euros/per capita/per year will not be able to provide prevention, health care for the whole population and additional holistic palliative care for patients within the statutory healthcare system.

Most significant issues facing hospice and palliative care in the next three years:

- The concern is that once the EU-funded project "Development of Palliative Care Services in the Republic of Serbia" (2011-2014) finishes, healthcare professionals will revert back to previous practices. The only opportunity may be if the country is able to develop at least some of the 30 planned palliative care units during the course of the project and experts support the work of the project and provide practical training.
- BELhospice, together with national and international supporters, plans either to build an independent inpatient hospice or to make an arrangement with a public hospital to rent a suitable space for this purpose. This unit may provide a good example of what hospice/palliative care should look like and how holistic care could be provided in the future. However, political will is needed to make this possible.

Implications for palliative care relating to the current economic crisis:

- The major challenge will be whether the government and the Ministry of Health are able to provide funding for what is planned within the Strategy of Palliative Care.
- The other issue will be if the economic crisis affects the level of donations and availability of national and international projects which might enable NGOs to establish and sustain palliative care services.

References

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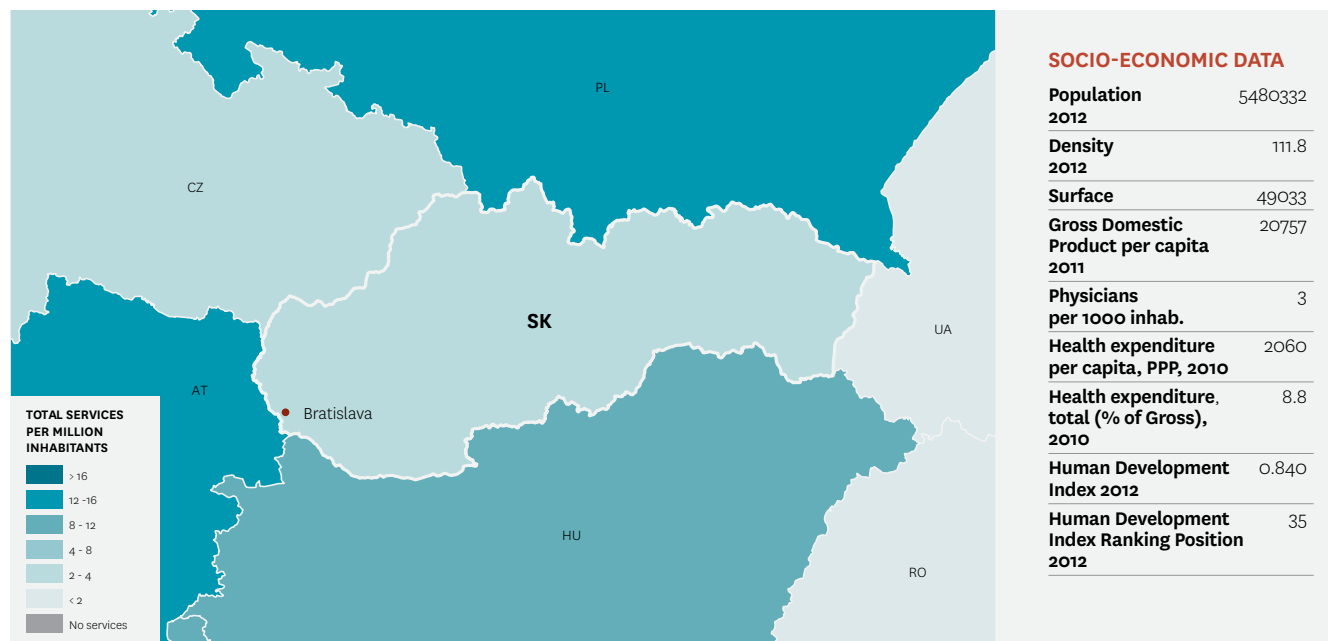
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 0 |
| Home palliative care support team | 0 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 1 (19) |
| Palliative care units in non-tertiary hospitals | 0 (92) |
| Inpatient hospice | 10 (166) |
| Day hospice/day care centre | 0 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- <http://www.plamienok.com/>
- Annual report from the National Health Information Center. Publication: Statistics of Inpatients in the Slovakian Republic (2010)

Additional comments:

- The National Cancer Institute (NCI) provides counseling services, pain treatment and symptom relief for palliative care patients and patients of all other medical departments. NCI provides palliative care services on both an inpatient (bed ward in the Department of Palliative Medicine and Clinical Oncology) and outpatient (clinic) basis. NCI has commenced collaboration with a small number of home care services and general practitioners with the aim of developing a home palliative care support team.
- Palliative care units in non-tertiary hospitals: Staff in these units are not highly qualified physicians and nurses (they have received no specialized palliative care training). The number of beds in these units is derived from compulsory reports by providers of inpatient healthcare to the National Health Information Center; this data suggests that although there are beds available for palliative care patients, these beds are mainly used for general nursing purposes.
- Five inpatient hospices have physicians and nurses who are trained in palliative medicine (physicians are usually former analgesicologists or oncologists). Some of these "hospices" have nursing beds only and lack comprehensively trained staff. Often neither physicians nor nurses have received any training in palliative medicine. There are some volunteers (but they are not trained either). There are also some initial palliative care activities in a few private hospices.

Palliative care services for children:

There is one paediatric home palliative care support team (a regularly licensed health care provider). All the services provided are financed by external donors.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

There is no information available at this time.

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- 2006 - Palliative medicine was recognized as a medical specialization by the Ministry of Health
- 2008 - A Chair of Palliative Medicine was established at Slovak Medical University in Bratislava.
- 2008 - A specialized medical journal "Palliative medicine and management of pain" commences publication in the Slovak and Czech languages (the idea of publisher Solen.sk and enthusiastic representatives of the Slovak and Czech palliative medicine associations).
- 2009 - The conference "Czech and Slovak Conference of Palliative Medicine" is held annually. In 2011, the meeting was organized in Bratislava (Slovakia); in 2012 it was held in Olomouc (Czech Republic).
- In 2012, four medical doctors completed a certification course as specialists in palliative medicine at Slovak Medical University in Bratislava.
- In Spring 2012, the Bjørnstjerne Bjørnson Institute of Palliative Care was established in Martin. It is a part of the Institute of Nursing at the Jesenius Faculty of Medicine. The Institute includes both a clinical department and an education and research centre.
(http://www.jfmed.uniba.sk/fileadmin/user_upload/editors/Oset_Files/The_Centre_of_Palliative.pdf).

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has remained the same.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: Nothing has changed since 2006 - no departments of palliative medicine have been established.
- Nursing homes: Nothing has changed since 2006 - there are no palliative care services in nursing homes.
- Residential homes for the elderly: - Nothing has changed since 2006 - there are no palliative care services in residential homes for the elderly
- Other community settings: Some sporadic activities in the field of home-based palliative care have commenced (but these are not covered by the compulsory health insurance scheme).

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

There is no information available at this time.

Perceived barriers to the development of hospice and palliative care:

- Generally scarce coverage of both hospital and home-based palliative care.
- Interest in palliative medicine amongst the general public and physicians is only increasing very slowly
- The ethics of palliative medicine are not generally adopted.
- The potential financial benefits of implementing comprehensive palliative care services (instead of other specialised acute care wards) are not sufficiently considered in the healthcare system.

Perceived opportunities for the development of hospice and palliative care:

- The concept of palliative care in the nursing community seems to be more favourable than in the medical community.
- Most home care initiatives are forward-thinking in terms of palliative care.
- Increased interest about palliative care among practitioners, oncologists and geriatricians.
- Increased interest about palliative care for senior citizens in residential and nursing homes.
- Pain management (algesiology) has been recognized as a medical specialty for more than ten years and there are more than fifty pain specialists throughout the country (this progress is supportive and encouraging for the development of palliative medicine).

Other issues relevant to the development of hospice and palliative care:

There is no information available at this time.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

The Slovak Association for Hospice and Palliative Care - Asociácia hospicovej a paliatívnej starostlivosti Slovenska (AHAPS) - was formed in 1999 and is representative of the whole country.

Directory or catalogue of palliative care services:

There is no information available at this time.

Congresses, scientific meetings or scientific journals in palliative care:

- The Czech and Slovak Conference of Palliative Medicine (Česko-slovenská konferencia paliatívnej medicíny) has been held annually since 2009, rotating between the Czech and the Slovak Republic; the conference is attended by approximately 150 participants.
- The journal Paliatívna medicína a liečba bolesti (Palliative Medicine and Pain Treatment) has been published three times per year since 2008, in both the Czech and Slovak languages (ISSN 1337-6896).

Palliative care research capacity:

There is no information available at this time.

Palliative care collaboration:

- There is palliative care collaboration between associations of hospice and palliative medicine and medical associations in the Slovak and Czech Republics.
- Pioneers in palliative care include the Slovak Association for Hospice and Palliative Care and personally-engaged individuals such as Stanislav Fabuš, Marta Kulichová, Leopoldína Šejdová, Alica Valkyová, Vladimír Chlebana, Kristína Križanová, and Patrícia Dobříková-Porubčanová.

Worldwide palliative care alliance level of development:

3B (Generalized palliative care provision): In terms of morphine availability, Slovakia should be categorised as 3b; however, in terms of the integration of palliative care into the healthcare system, Slovakia should be categorised as 4a (palliative care services are at a stage of preliminary integration into mainstream healthcare service provision, but this is only the beginning of the process).

There has been some increase in the number of home-based palliative care services. In 2008, a specialized medical journal commenced publication in the Slovak and Czech languages. The conference "Czech and Slovak Conference of Palliative Medicine" is held annually

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

The Bjørnstjerne Bjørnson Institute of Palliative Care in Martin is a part of the Institute of Nursing at the Jessenius Faculty of Medicine. The Institute includes an education and research centre.

(http://www.jfmed.uniba.sk/fileadmin/user_upload/editors/Oset_Files/The_Centre_of_Palliative.pdf).

Specific developments in under-graduate palliative care education initiatives:

- Medicine: There has not been much development. There are some palliative care education initiatives at the Medical Faculty in Martin and in Bratislava (but only within the frame of general oncology).
- Nursing: It is possible to write a thesis in palliative care at the Institute of Nursing at Jessenius Faculty in Medicine in Martin.
- Social work: In the last five years there have been a large number of health-care professionals that have graduated as social workers in Slovakia. They are often interested in being employed in palliative care and hospice units, but because of organizational and reimbursement obstacles they are not usually employed in these institutions.
- Other professions: No development.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: Following the new legislation about postgraduate medical specialization, the accreditation process commenced (palliative medicine has been accredited in 2012 at the Slovak Medical University in Bratislava for postgraduate and also for undergraduate students).
- Nursing: In 2013, a Master's degree in palliative care for nurses will be available at the Institute of Nursing at Jessenius Faculty in Medicine in Martin.
- Social work: No development.
- Other professions: No development.

Translation of palliative care documents or other materials:

The Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organisation of palliative care) has been translated in the Slovak and Czech language. This translation was published in the Czech and Slovak journal "Palliative medicine and the management of pain".

Initiatives to develop healthcare professional leadership in palliative care:

There have been some initiatives to develop healthcare professional leadership in palliative care.

Officially recognized medical certification:

Since 2008, palliative medicine has existed as a sub-specialty in Slovakia for clinical oncology, family medicine, geriatrics, internal medicine, neurology, pediatrics and intensive care medicine. The sub-specialty consists of two components – theory and practice. The theory component contains the following elements: pain treatment; symptom relief; psychological and ethical issues; diagnostics and therapy of acute complication; managing palliative care. The practice component is composed of: palliative record; prognosis and therapeutic plan; diagnostic procedures and evaluation of results; monitoring of therapeutic effect; procedures, diagnostic, therapy and planning in the outpatient palliative care clinic; communication skills; decision making about the most appropriate place of care for the patient (palliative care department, at home, in hospice, in general hospital); counseling with and for other specialists; skills in distinctive palliative care interventions; and pediatric palliative care. To date, four professionals have been accredited in Slovakia.

Capacity of palliative care workforce training in Universities and Medical Schools:

- Slovakia has four medical schools and an estimated two of them offer palliative care within the curriculum of clinical oncology (it is not known whether they are optional or mandatory components).
- There is an estimated one full Professor in Geriatrics (responsible for teaching palliative medicine) and an estimated two "other professors".

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- Essential medications are generally available throughout Slovakia.
- Some medications are available but not free of charge; for example, haloperidol and butylscopolamin are available on prescription, but require direct payment from the patient. Some other medications (for example, midazolam in ampoule form) are available on prescription from a specialist (and are co-funded).

Developments/opportunities/barriers relating to the accessibility of essential medications:

- There is no possibility for a general practitioner to prescribe essential medications; they can only be prescribed by a specialist (pain specialist, oncologist or palliative medicine specialist).
- General practitioners need to be able to prescribe essential medications for home-based palliative care patients
- There are many barriers to prescribing essential medications: patients and families have to go from one specialist to another to obtain their prescription; because GPs don't have an opioid prescription license, they don't know how to effectively manage pain with opioids.

Developments/opportunities/barriers relating to the affordability of essential medications:

Many essential medications involve some form of co-payment by the patient (it was announced recently that co-payment from patients will be increased).

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

There have been such initiatives, mainly in the mass media (TV, newspapers). However, there is almost no education or training initiatives on this issue either in the Slovak Medical Universities or in the postgraduate education of internists and practitioners.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

- There have been such initiatives, but only in relation to exceptionally expensive medications. Most opioids are not generic and consequently are expensive (only fentanyl TDS is an exception to this).
- General opioid policy in Slovakia prefers generic as opposed to original opioids.

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

In 2012, four doctors completed a specialist course in palliative medicine at Slovak Medical University, and the Bjørnstjerne Bjørnson Institute of Palliative Care was established in Martin as part of the Institute of Nursing at the Jessenius Faculty of Medicine

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

The most important new legal or policy change was recognising palliative medicine as a medical specialty in 2006.

The impact of these policy changes and ways in which they have been important:

It is now formally permitted to educate physicians and students of medicine about palliative care.

Development of a national palliative care consensus:

There is no palliative care framework, and there are no standards or guidelines; however, it is expected that regulations and norms for palliative care outpatient clinics and mobile palliative home care teams will be developed in the near future.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

A national meeting was organised on Oct. 15th 2009 in Bratislava: How to design, implement and evaluate palliative care services and programs, supported by WHO country office and the Ministry of Health. The key speakers were X. Gomez-Batiste, director of WHO collaborating center for public health palliative care programs, K. Repková, director of Institute for Labor and Family Research in Bratislava, and Kristína Križanová, Department of Palliative Medicine of Clinic of Oncology, National Oncology Institute, Bratislava, Slovakia. The meeting was designed for stakeholders and professionals involved in decision-making about palliative care. Delegates from the main health insurance companies agreed that palliative care is important for patients in need but did not make any binding financial commitments. However this meeting was very helpful for the future development of palliative care in Slovakia.

Development of an advocacy framework for integrating palliative care into the health care system:

The Association for Hospice and Palliative Care has been working on the development of palliative care in Slovakia for more than ten years. Its members are mainly providers of hospice care in Slovakia, but there also some other supportive people involved. People work together to obtain better contracts from the health insurance companies and meet with some members of the Slovak parliament to lobby for improved payments for palliative care.

Strategies to improve political awareness and government recognition of palliative care:

Since 2006, Slovakia has had four Ministers for Healthcare. With each appointment there has been a replacement of administrative officers and chief officers from main sections of the Ministry of Health. Representatives of palliative care tried to meet every one of them but it was very difficult to explain the palliative care agenda to them all. On two occasions, success was achieved: once when palliative medicine was accepted as a medical specialty and a second time with the enlistment of palliative care outpatient clinics into the healthcare provider network.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

There is no information available at this time.

Involvement with the European Union in relation to hospice and palliative care initiatives:

There is no information available at this time.

Development of initiatives framing palliative care as a 'human right':

There is no information available at this time.

General legislation relating to palliative care:

- Act No 576/2004 of Statute, about health care, services associated with providing health care and about change and amendment of some acts.
- Act No 577/2004 of Statute, about the range of health care covered by compulsory health insurance schemes and about payment for services associated with providing of health care.
- Act No 578/2004 of Statute, about providers of health care, about medical staff, about professional organizations and about change and amendment of some acts.
- The Journal of Ministry of Health of Slovakian Republic, section 32-51, volume 56.

Published national documents relating to palliative care standards and norms:

The Journal of Ministry of Health of Slovakian Republic, special edition, 19.6.2006, Concept of health care in the division of palliative medicine including hospice care, No 17463/OZS.

National Plan or Strategy of Palliative Care:

There is a National Strategy of Palliative Care in progress: palliative medicine has to be integrated into the National Plan for Oncology and this plan has been under preparation for a number of years already.

National Cancer Control Strategy:

National Plan for Oncology

National HIV/AIDS Strategy:

- <http://www.hivaid.sk/index.php/np-prevenicie-hivaid>
- The National Plan on Prevention of HIV/AIDS in Slovakian Republic (2009–2012) does not contain an explicit reference to palliative care provision.

National Primary Health Care Strategy:

There is no information available at this time.

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

There is a position of "main expert of palliative medicine" at the Ministry of Health.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- There is a process of double prescription; a double sheet with the blue streak for strong opioids. Tramadol, dihydrocodeine and codeine are prescribed on the common prescription sheet. Strong opioids can be prescribed only by oncologists, algesiologists, rheumatologists and orthopaedists. All opioids are available by prescription for outpatients in the pharmacies and also for inpatients in hospitals.
- Pain guidelines: Algesiologia (Algeziológia) (2005) EDIS - MONOGRAFIE, 1st edition, ISBN 80-8070-445-7. Editor: Dr. Marta Kulichová. http://www.pain.sk/standardy/standardy_oo.php

Funding of palliative care services:

- There is no payment required for palliative care consultation or hospitalisation
- Partial payment is required for palliative care medications: complex and complicated regulations are based on the categorization and pricing of medication. Approximately one-third of medications are fully covered (without co-payment from the patient); approximately one-fifth of medications have a maximum one Euro co-payment. The average co-payment was about 7.35 Euros per package in 2011. The maximum co-payment for "socially handicapped" people is limited to 30 Euros or 45 Euros quarterly (depending on the social category).

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:
There has been a change in public awareness of hospice and palliative care.

Major public discussion, debate or controversy about hospice and palliative care:

In almost every newspaper there is an article about hospice and palliative care (but there is no major public discussion about it).

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

Since 2006, there have been no civic society groups relating to palliative care established in Slovakia. People do not have the necessary skills to advocate for their own basic rights. There is also apprehension that "palliative" means "non-curative". Slovak health services are underpaid and social services are very poor. Health and social services do not collaborate with each other.

Hospice or palliative care 'success' stories:
There is no information available at this time.

Initiatives seeking the legalisation of euthanasia or assisted dying:
In Slovakia there is no initiative for the legalization of euthanasia.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

Unfortunately, in the next few years hospice and palliative care will probably remain a "Cinderella" discipline in health care in Slovakia in relation to "Winning" medicine (people are afraid to lose hope for "cure"). People are not well-prepared for death and some old people are not ready to die. In 2012, a DRG system is to be implemented in the Slovak healthcare system (not a very palliative care - friendly reimbursement method).

Most significant issues facing hospice and palliative care in the next three years:

The main mission is to teach young, skilled physicians about palliative medicine; there are only four people that have received such training, but it is hoped that this can be improved through publication of the journal and annual meetings negotiating with health insurance companies.

Implications for palliative care relating to the current economic crisis:
Palliative care somehow needs to be implemented into the Slovakian healthcare system; this may have to be achieved on a "patchwork" basis during the current economic crisis.

References

Krizanová K. 2002. "Slovakia: cancer pain management and palliative care". *J Pain Symptom Manage*; 24(2):231-2."

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 7 (12) |
| Hospital palliative care support team | 16 (n/a) |
| Home palliative care support team | 0 |
| Mixed palliative care support team | 2 |
| Palliative care units in tertiary hospitals | 2 (16) |
| Palliative care units in non-tertiary hospitals | 3 (24) |
| Inpatient hospice | 1 (12) |
| Day hospice/day care centre | 1 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Tatjana Fink/Hospic, 3.1.2009/1.1.11
- For adult teams: Pilot project - final report for three regions in Slovenia, Golnikski simpozij: Paliativna oskrba, 3.0M.2011
- www.esmo.org/index.php?id=l535
- Mateja Lopuh
- Urska Lunder
- Jozica Cervek
- Maja Seruga

Additional comments:

- Tatjana Fink is President of the Slovenian Hospice Association. There is one hospice house in Ljubljana with 12 beds.
- The number of beds varies among institutions. In the majority of institutions, palliative care beds are located in other departments (long term care, etc.)
- Hospital palliative care support teams are in the process of development. There are approximately eight beds per hospital palliative care support team.
- Mixed palliative teams work in General Hospital (GH) Jesenice as mobile teams to support patients at home and in Golnik to support patients after they have been discharged home.
- There are two officially recognized palliative care units in tertiary hospitals - at the Institute of Oncology, Ljubljana and University hospital Golnik (both have international accreditation from ESMO) (approximately sixteen beds in total).
- The number of beds in palliative care units in non-tertiary hospitals is estimated.
- A day care centre is organized as a part of the outpatient clinic in GH Jesenice. There is art therapy, music therapy and physiotherapy available on request.

Palliative care services for children:

There is one paediatric hospital palliative care support team located in the tertiary centre in Ljubljana that offers a consultation service. There are specialist bereavement teams for children in Ljubljana and Maribor.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|------|--|
| 1995 | The non-governmental organisation, Slovenian Hospice Association is founded, providing professional and voluntary home hospice care, and palliative care education. |
| 1998 | The Slovenian Hospice Association gains recognition from the Ministry of Health. |
| 1999 | National guidelines for pain management are published, and the WHO book Pain and Symptom Management for Children with Cancer is translated into Slovenian. |
| 2000 | The non-governmental organization Palliative Care Development Institute is founded, with the aim of developing palliative care education and research, and increasing contacts with the Ministries of Health and Social Welfare. The Institute plays a crucial role in the strategic planning and policy development of palliative care at the national level. |
| 2004 | The first hospital palliative care ward (with four beds) is opened at General hospital Golnik. |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- Founding of the Professional Palliative Care Board Committee as an advice body for the Minister of Health.
- National Palliative Care Programme (NPCP) confirmed by Slovene parliament
- Action Plan established for implementing the NPCP.
- Pilot project at the Ministry of Health: Organized Implementation of Palliative Care in three Slovene regions (June 2009–Oct 2010), with the publication of a book providing details of the results, description of the processes of organization of palliative care at all levels of the health care system, the evaluation methods and presentation of the documentation.
- ESMO Certification for Excellence in Medical Oncology and Palliative Care: Oncology Institute Ljubljana in 2009 (re-certified 2012), and University Clinic Golnik in 2010.
- Establishment of Slovene Palliative Medicine Society, October 2011.
- Undergraduate education of medical and nursing students in palliative care
- Certified palliative care postgraduate education for medical professionals
- Several professional publications.
- Research achievements: 7th frame EU project OPCARE 9 (February 2008–March 2011), retrospective research projects in different institutions, research studies on palliative care needs, studies on communication and attitudes.
- Nomination of Mateja Lopuh as the national coordinator of the NPCP by the Ministry of Health in 2012.

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has improved modestly.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: Tertiary level - three palliative care units (Oncology Institute, University Clinic Golnik, University Clinic Maribor); General Hospitals: Palliative care consultant services in several hospitals.
- Nursing homes: Fuzine in Ljubljana.
- Residential homes for the elderly: Hospice house in Ljubljana.
- Other community settings: Primary palliative care network in progress.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

There has been an expansion from a focus on cancer patients to address the needs of 'non-cancer' patients.

Perceived barriers to the development of hospice and palliative care:

- Palliative care services are not included in the health insurance company contracts.
- There are not enough medical professionals educated in palliative care.
- Patients are not aware of the potential benefits of palliative care.

Perceived opportunities for the development of hospice and palliative care:

- There is some interest in palliative care education – incorporation of palliative care in the regular education of medical professionals and in other disciplines (social work, psychology, etc.).
- Recognition of the benefits of palliative care from other specialties.
- Public and patient association demands for good-quality palliative care.

Other issues relevant to the development of hospice and palliative care:

- Development of Slovenian NPCP and Action plan for palliative care and the acceptance of both documents by the government.
- Pilot project on implementation of organized palliative care in three regions of Slovenia supported by the Ministry of Health.
- Establishment of the first hospice house in Ljubljana.
- Founding of the Slovene Palliative Medicine Society.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

The Slovenian Palliative Medicine Society (Slovensko združenje paliativne medicine) was formed in 2011 and is representative of the whole country.

Directory or catalogue of palliative care services:

A catalogue of palliative care services is in progress: "Hospic Catalogue" includes available palliative care services and relevant .

Congresses, scientific meetings or scientific journals in palliative care:

- A symposium on palliative care is organised by the University Clinic of Golnik on an annual basis.
- A Palliative Care School has been organized by the Institute of Oncology, Ljubljana since 2008 (once to twice per year); approximately 200 people have attended each School.

Palliative care research capacity:

- Research centres include: IORC (International OPCAREQ Research Consortium); International Reference Group for Liverpool Pathway for the Dying; Research center at the Palliative Care Department at the Institute of Oncology, Ljubljana.
- Researchers include: Urška Lunder, Maja Ebert Moltara, Jernej Benedik, Jožica Cervek, Mateja Lopuh, Maja Seruga, Tanja Zagar, Tina Jeric, Branka Cerv, Andreja Petemelj, Majda Pahor, Anja Simonc, Nevenka Krceviski Skvarc, Slavica Lahajnar, Mateja Lopuh.
- urska.lunder@mail.ljudmila.org/mateja.lopuh@gmail.com/oerfek@onko-1.sl/jbenedik@onko-1.si/tazagar@onko-1.si/branka-cerv@hotmail.com/slahajnar@onko-1.si/maja.seruga@guest.ames.si/simonc@klinikagolnik.si, andreja.petemelj@klinikagolnik.si, nevenke.krceviski.skvarc@amis.net.

Palliative care collaboration:

- There is palliative care collaboration involving:
 1. Institute for Palliative Medicine at San Diego Hospice - University Clinic Golnik (leadership programme) (education, mentoring in leadership and strategic planning).

2. Institute of Oncology Ljubljana - Hospice House Ljubljana (regular meetings of staff)
 3. General hospital Jesenice - Regional hospice committee (regular meetings of staff)
 4. Alpe Adria (Italy, Croatia, Austria)
 5. IORC (nine European Countries)
 6. EU Project OPCARE 9
 7. Leadership Development Programme in Palliative Care (Mentor: Professor Lukas Radbruch, Bonn, Germany)
- Palliative care pioneers include: Metka Klevisar (hospice development), Urska Lunder (palliative care development at the national level), Jozica Cervek and the team at the Institute of Oncology, Ljubljana (acute palliative care), Mateja Lopuh and the team at GH Jesenice (specialized ambulatory palliative care), Maja Seruga (palliative medicine in internal medicine), Nevenka Krceviski Skvarc (pain management at the national level), and Tatjana Zargi (hospice development).
 - World Hospice and Palliative Care Day initiatives include: regular scientific symposia on the occasion, several publications, public forums (organized by hospices), workshops on psychosocial themes (organised by hospices), articles in different newspapers, public lectures, etc.

Worldwide palliative care alliance level of development:

3A (Isolated palliative care provision) – 3B (Generalized palliative care provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

There have been several 50-70 hour courses organized to provide doctors and other healthcare professionals with a diploma of special knowledge and skills in palliative care.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Medical Faculty Maribor – 15 hours palliative care education in the last semester; Medical Faculty Ljubljana – eight hours palliative care education (Gerontology).
- Nursing: An elective course on palliative care at College of Nursing Jesenice; College of Nursing Ljubljana; College of Nursing Izola; College of Nursing Celje; College of Nursing Maribor.
- Social work: A seminar on palliative care is provided in the last semester of the social work curriculum.
- Other professions: Psychology – there is a seminar and individual projects on palliative care.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: - Rotation in palliative care wards for some specialties (emergency, medical oncology, radiation oncology, interns, general practitioners); Special skills diploma in palliative care accredited by Slovenian Medical Society.
- Nursing: Special skills diploma in palliative care accredited by Slovenian Medical Society.
- Social work: Special skills diploma in palliative care accredited by Slovenian Medical Society.
- Other professions: Special skills diploma in palliative care accredited by Slovenian Medical Society for pharmacists, psychologists, etc.

Translation of palliative care documents or other materials:

- Edmonton palliative care pathway.
- Liverpool pathway for dying patients.
- Essential medicines in palliative care, 2nd edition (2012).
- Common questions about palliative care, Institute of Oncology, Ljubljana (2008).

Initiatives to develop healthcare professional leadership in palliative care:

Faculty development is in process through cooperation with palliative care experts in the country and the organization of the Diploma in education on palliative care knowledge and skills provided by the Slovene Palliative Medicine Society.

Officially recognized medical certification:

- Slovenia currently has palliative care accreditation in process; courses organised by the Slovenian Palliative Medicine Society will soon be available and application for their official recognition will be issued at the Slovenian Medical Society in 2012.
- A 60 hour course in palliative care is also available.

Capacity of palliative care workforce training in Universities and Medical Schools:

- Slovenia has two medical schools, both of which have palliative medicine as an optional component (one in Ljubljana and one in Maribor).
- There is one assistant professor of palliative medicine and one “full professor non-medical”.

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- Practically all opioids on the list of essential medications as well as other medications used in palliative care are available in Slovenia free of charge (alternative medications may be available if required).
- There are some individual initiatives relating to opioid availability (for example, EU – Access to Opioid Medications in Europe (ATOME project)).

Developments/opportunities/barriers relating to the accessibility of essential medications:

There is no information available at this time.

Developments/opportunities/barriers relating to the affordability of essential medications:

All opioids in Slovenia are available free of charge for patients.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

Slovenia has participated in the ATOME project (but there are no such restrictions in Slovenia).

Initiatives to promote attitudinal change in relation to ‘opiophobia’:

- There have been many lectures and publications for professionals and the general public in relation to ‘opiophobia’.
- A survey has been conducted on the use of opioids and a booklet about opiophobia is due to be published soon.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no need for such initiatives in Slovenia as essential medications are available free of charge.

Initiatives that consider access to essential medication as a legal and human right:

Access to essential medication as a legal and human right is in the Slovenian constitution.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- Development of the NPCP and the Action Plan, together with the Pilot Project of organized implementation of palliative care in three regions of Slovenia.
- Nomination of the national coordinator of the NPCP.

The impact of these policy changes and ways in which they have been important:

The above documents represent a legal basis for the development of palliative care. The major impact so far:

- Increased awareness among both healthcare professionals and the general public.
- An increase in palliative care education activities.
- Increased interest among health care institutions in relation to organized palliative care activities.
- Increased media coverage of palliative care themes and stories.

Development of a national palliative care consensus:

To date, there have not been official guidelines in palliative care published in the Slovenian language; the report of the pilot study with the description of the processes and proposed documentation serves as a tool for guidance.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

- There have been two meetings supported by the Slovene WHO Office and the Ministry of Health: one to accept the NPCP and another to develop the Action Plan.
- ATOME Group Meeting (EU project on availability of opioids in Central and Eastern European countries).

Development of an advocacy framework for integrating palliative care into the health care system:

The NPCP with an Action Plan and Pilot project for its implementation.

Strategies to improve political awareness and government recognition of palliative care:

Initiatives by health care institutions, hospices, the Professional Palliative Care Board Committee and other individuals.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

- Ministry of Health: Pilot project for implementation of organized palliative care in three regions.
- City of Ljubljana (building Hospice House).

Involvement with the European Union in relation to hospice and palliative care initiatives:

- Participation as a partner in the 7th frame EU project: OPCAREg (European collaboration in establishing better quality of life in the last days of life of cancer patients).
- Cooperation as a partner country in the EU Project ATOME (establishing better conditions of opioid availability).

Development of initiatives framing palliative care as a 'human right':

The Law on Patients Rights (2008), includes a section on the right for palliative care, rights in relation to informed consent, advanced directives, and Will of Attorney; the law establishes the patient as an autonomous subject, who has full power in making decisions (or their surrogates, when appropriate). It is even stated that advanced directives chosen by a patient must be honoured by healthcare professionals (otherwise it is understood as a medical and legal error).

General legislation relating to palliative care:

- The Law on Patients' Rights (2008), the NPCP and associated Action Plan.
- Essential medicines in palliative care, 2nd edition, 2012, Institute of Oncology Ljubljana.
- Common questions about palliative care, 2008, Institute of Oncology Ljubljana.

Published national documents relating to palliative care standards and norms:

- Opioids in Palliative Care (2012): Najpogostejša vpražanja v paliativni oskrbi (published by the Institute of Oncology).
- Essential medicines in palliative care, 2nd edition 2012, Institute of Oncology Ljubljana.
- Common questions about palliative care, 2008, Institute of Oncology Ljubljana.

National Plan or Strategy of Palliative Care:

The NPCP (adopted in April 2010) describes the structures and processes at all levels of palliative care, the number of beds needed, the number of coordinators required, and the network between all these structures.

National Cancer Control Strategy:

One chapter in the National Cancer Control Plan is dedicated to palliative care; it summarizes the NPCP.

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy but it does not contain a reference to palliative care provision.

National Primary Health Care Strategy:

There is a National Primary Health Care Strategy but it does not contain a reference to palliative care provision.

Designated policy maker for the delivery of palliative care services:

The Department for Health is the designated policy maker for the delivery of palliative care services.

Department of Health specific responsibility for the delivery of palliative care services:

According to the NPCP, the Ministry of Health is the responsible body for organising and implementing palliative care in the Slovenian healthcare system.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

Monitoring of palliative care is defined in the Action plan of the NPCP and has to be implemented as the NPCP develops.

Opioid legislation/Pain guidelines:

- A prescription can be written by any licenced medical doctor practising in Slovenia: it is valid for five days; it has to be written in duplicate; opioids can be prescribed for one month per one prescription; strong opioids can be obtained in every pharmacy and in all hospitals (not necessarily on the same day).
- Printed pain guidelines are available: Lahajnar Cavlovic et al: Prescribing strong opioids to cancer patients; and Essential medicines in palliative care, 2nd edition (2012).
- Further pain guidelines are in progress: a working group of the Slovenian Pain Society has been working on guidelines for the treatment of non-malignant pain.

Funding of palliative care services:

There is no payment required for palliative care consultation, hospitalisation or medications.

In 2009, a pilot project at the Ministry of Health "Organized Implementation of Palliative Care in Three Slovene Regions (2009 - 2010)" detailed the organization of palliative care at all levels of the Slovenian health care system and National Clinical Protocols in Palliative Care

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:
Patients often enquire about palliative care services themselves, which demonstrates a rise in the awareness of hospice and palliative care among the general public.

Major public discussion, debate or controversy about hospice and palliative care:

There have been organized forums in the capital city Ljubljana for World Hospice and Palliative Care Day (and also organized forums in different regions of Slovenia).

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

There is great interest about hospice and palliative care within different media: a monthly talk show on regional television, many publications in different newspapers, presentations of books, interviews, comments on the news, stories, etc.

Hospice or palliative care 'success' stories:

- Gorenjska primary care network: initiatives from several primary health centres, first structured course in palliative care (60 hours) to educate all members of the palliative care team.
- A book of stories about patients receiving palliative care (written by a doctor); a second edition was required three weeks after initial publishing by a major Slovene publisher.
- Education activities in postgraduate palliative care courses (see above).
- Essential medicines in palliative care, 2nd edition (2012).
- ESMO Certification for Excellence in Medical Oncology and Palliative Care: Oncology Institute Ljubljana in 2009 (re-certified 2012), and University Clinic Golnik in 2010.
- Establishment of Slovene Palliative Medicine Society, October 2011.
- Nomination of the National Coordinator of the NPCP (2012).

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is no information available at this time.

References

Lunder U. Cerv B. 2002. "Slovenia: status of palliative care and pain relief". *J Pain Symptom Manage*; 24(2):233-5.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

- Further palliative care education of all healthcare professionals is needed.
- There is increased interest about palliative care among patients and their relatives.
- Increased acknowledgement of the benefits of palliative care is required.
- Better integration of palliative care in the routine practise of oncology is needed.

Most significant issues facing hospice and palliative care in the next three years:

- Education, the motivation of medical experts, and promotion of palliative care among lay people.
- Organizational solutions to offer better forms of palliative care.
- Research of cultural specifics in palliative care provision.
- Increased international cooperation.
- Implementation of the NPCP.

Implications for palliative care relating to the current economic crisis:

- Positioning palliative care within the established healthcare programme (and finding funds to achieve this)
- More support for palliative care will be needed due to the rising population of socially and economically deprived patients at the end of life in Slovenia.

Spain¹

NATIONAL ASSOCIATION/KEY CONTACT

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 59 |
| Home palliative care support team | 166 |
| Mixed palliative care support team | 38 |
| Palliative care units in tertiary hospitals | 34 (340) |
| Palliative care units in non-tertiary hospitals | 77 (1520) |
| Inpatient hospice | 1 (15) |
| Day hospice/day care centre | 2 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Directorio SECPAL de Cuidados Paliativos 2012
- www.secpal.com/directorio

Additional comments:

There is no additional information available at this time.

Palliative care services for children:

There are two paediatric hospital palliative care support teams and three paediatric palliative care units in tertiary hospitals.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|------------------|--|
| 1984-1991 | First Palliative Care Services and Units: H. Valdecilla Santander, Hospital Santa Creu, Vic (Barcelona), Hospital El Sabinal (Las Palmas de Gran Canarias), Hospital Gregorio Marañón de Madrid. |
| 1990-1995 | Catalonia WHO Demonstration Project on Palliative Care. |
| 1991 | First Home Care Team of the Spanish Association Against Cancer. |
| 1992 | Spanish Society of Palliative Care was founded. |
| 1994 | The Spanish Ministry Decree improves the availability of strong opioids. |
| 1994 | First issue of "Medicina Paliativa" Spanish Journal of Palliative Care. |
| 1995 | First Spanish Congress on Palliative Care and 4th European Congress in Barcelona. |
| 1997 | First Edition of the Spanish Directory of Palliative Care. |
| 1999 | www.secpal.com (a web site for Spanish healthcare professionals) is launched. |
| 2001 | National Plan on Palliative Care from Spanish Minister of Health. |
| 2004 | Sociedad Española de Cuidados Paliativos (SECPAL) marks the publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organisation of palliative care) by translating the document into Spanish and Galician. |
| 2005 | Palliative care is included in the 'Plan Nacional de Cáncer' - the Ministry of Health recommends its implementation and recognizes palliative care as a human right to be protected. |
| 2006 | A new national plan is under consensus, and five regions are in the process of implementing palliative care plans. |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- In 2007, the National Ministry of Health launched the "Estrategia en Cuidados Paliativos en el Sistema Nacional de Salud" (Palliative Care Strategy in the National Health Service). The strategy was a strong commitment to palliative care by regional governments and social agents (including scientific associations) that focused on promoting accessibility and equity to high quality palliative care across the country. Previously, every region had its own model of provision.
- After the publication of this document, many regional Ministers of Health launched Regional Palliative Care Plans (Madrid, Galicia, Asturias, Cantabria, Baleares, Murcia, Aragon and Andalucía followed the plans previously developed in Cataluña and Extremadura). Many new palliative care services were developed within regional health services across the country (an increase from 257 services in 2004 to 420 services in 2011).
- The Spanish Association against Cancer (Asociación Española Contra el Cancer, AECC) decided not to support the further development of palliative care services (there was approximately 100 home care teams in 2006), because public home care teams were already implemented throughout the country; this "process of conversion" is currently ongoing.
- New Laws about "Death process and Dignity" were launched in three regions of Spain (Andalucía, Aragón and Navarra). These Laws included the right to receive palliative care for all citizens.

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: There has been much improvement (an increase from 113 services in 2004 to 206 in 2011). However, there is a lack of acute palliative care units in large general hospitals.
- Nursing homes: These types of services are quite unusual in Spain.
- Residential homes for the elderly: Formal palliative care is rarely provided in these residential units (end of life care in these settings is underdeveloped).
- Other community settings: There has been much improvement (an increase from 143 services in 2004 to 203 services in 2011). However, despite the implementation of new services, palliative care teams are still unable to provide care in many rural areas.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

Since 2003, all terminally-ill patients (including non-oncological patients) have the right to receive palliative care. However, in Spain access to specialized palliative care units by non-oncological patients is very low in comparison to oncological patients.

Perceived barriers to the development of hospice and palliative care:

- Difficulties in the identification of patients as "terminally-ill"
- Lack of official certification (specialization) of palliative care professionals.
- Inequity and difficulties in accessing palliative care services for some groups of patients (for example, non-oncological patients, children and patients in rural areas).

In 2007, the Ministry of Health launched the Palliative Care Strategy in the National Health Service, a strong commitment to palliative care by regional governments that focused on promoting accessibility and equity to high quality palliative care across the country

Perceived opportunities for the development of hospice and palliative care:

- Palliative care is included in legislation as a basic right for every citizen in Spain.
- There is special interest in palliative care from the Spanish government; their representatives meet every six months with key stakeholders in palliative care and leaders from regional governments.
- There are many healthcare professionals (mainly doctors) who are well trained in palliative care, and very interested in developing the discipline in Spain.

Other issues relevant to the development of hospice and palliative care:

The number of medical schools in Spain has increased by more than 50% since 2001. There are currently more than 40 medical schools in the country and many have implemented palliative care programmes within their curricula.

Vitality

THE VITALITY OF PALLIATIVE CARE**National Associations of Palliative Care:**

- The Spanish Society for Palliative Care (Sociedad Española de Cuidados Paliativos) was formed in 1992; the association has a website (www.secpal.com) and is representative of physicians, nurses, social workers and psychologists working in the field of palliative medicine throughout the country.
- The National Association for Palliative Nursing (Asociación de Enfermería en Cuidados Paliativos (AECPAL)) represents nurses working in palliative care and works in close collaboration with the national association. In addition, almost all regions of Spain have a regional society that works closely with SECPAL.
- There is another Spanish association that promotes the development of palliative care in resource-poor countries: Palliative without frontiers (Paliativos Sin Fronteras) was formed in 2007.

Directory or catalogue of palliative care services:

- There is a printed directory of palliative care services: Directorio SECPAL de Cuidados Paliativos (first edition, 1997; latest edition, 2004).
- Online version: www.secpal.com/directorio (first edition, 2000; latest edition, 2012).

Congresses, scientific meetings or scientific journals in palliative care:

- SECPAL host a National Palliative Care Congress on a biannual basis, attended by approximately 1100 participants.
- The journal "Medicina Paliativa" is published four times per year (EMBASE).

Palliative care research capacity:

- Research centres include:
 - Instituto Cultura y Sociedad (ICS), Medicina Paliativa Clínica, Universidad de Navarra (<http://www.cun.es/la-clinica/servicios-medicos/departamento/medicina-paliativa>)
 - Qualy-Ico (<http://www.iconcologia.net/catala/qualy/observatori.htm>)
 - Orcpex-Observatorio Regional de Cuidados Paliativos de Extremadura (www.orcpex.org)
 - Observatorio de Cuidados Paliativos Hermanas Hospitalarias (Palencia) (www.observatoriodepaliativos.org)
- Researchers include:
 - Centeno, C., (www.cun.es)
 - Espinosa, J., (<http://www.iconcologia.net/catala/qualy/observatori.htm>)
 - Flores, LA., (www.observatoriodepaliativos.org)
 - Gómez-Batiste, X., (<http://www.iconcologia.net/catala/qualy/observatori.htm>)
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 - Noguera, A., (www.lagunacuida.org/)
 - Pascual A., Nabal, M., Núñez JM, Gómez M, Rocafort J, Boceta J, Benítez MA, Sanz A, Alonso A, Porta J, Cuervo MA, Guanter L, Gisbert A, Carvajal A, Lacasta M.

Palliative care collaboration:

- The World Health Organization Collaborating Centre for Public Health Palliative Care Programmes: The Centre was created in 2008 to promote the development of national palliative care programmes through a public health approach in countries that require support. Based on experience gained in Catalonia over 15 years as a WHO Demonstration Project for Public Palliative Care, the ultimate aim of the collaborating centre is to build up a large portfolio of activities in knowledge translation, research, training, advocacy and expert advisory commitments for the WHO, the countries requiring support and health authorities (both in Spain and internationally). The focus of the Centre is on the organization, implementation and quality assessment of palliative care services and programmes. The Centre is also very interested in the practical aspects of palliative care development and implementation.

http://www.iconcologia.net/catala/qualy/centre_descripcio.htm
- Pioneers include: Hospital el Sabinal, Las Palmas de Gran Canaria; Hermanos Hospitalarios de San Juan de Dios; Hospital de Valdecilla, Santander; Hospital Gregorio Marañón, Madrid; Spanish Association Against Cancer (AECC); "Vida als Annys" program, Catalonia.
- All Spanish associations of palliative care celebrate and promote World Hospice and Palliative Care Day in a variety of ways every year.

Worldwide palliative care alliance level of development:

4b (Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision).

Following the publication of this document, many regional Ministers of Health launched Regional Palliative Care Plans and new palliative care services were developed within regional health services across the country

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

The National Health System Strategy for Palliative Care (2007) defined a number of objectives related to education and training. A large amount of money (7,000,000 euros per year) was transferred from central government to regional governments in order to achieve these objectives. Many palliative care education and training initiatives have now been implemented throughout the country.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: More than ten new medical schools have been created; many of them have palliative care training for undergraduate students.
- Nursing: The number of nursing schools providing undergraduate training in palliative care has increased (from 50% of schools to almost 100%).
- Social work: No data available but it is thought that there are no major initiatives in this area.
- Other professions: No data available about undergraduate training for psychologists, physiotherapists, etc.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: An additional Master Degree in Palliative Medicine has been created, and the first Chair in Palliative Medicine has been created at the University of Vic.
- Nursing: The first Master Degree in Palliative Nursing has been implemented in the University of Navarra
- Social work: No data available.
- Other professions: No data available.

Translation of palliative care documents or other materials:

The following four documents have been translated.

1. De Lima L. The International Association for Hospice and Palliative Care List of Essential Medicines for Palliative Care. *Palliative Medicine*. 2006; 20:647-51.
Translated as: De Lima L. Asegurando la disponibilidad de medicamentos: desarrollo de una lista de medicamentos esenciales en Cuidados Paliativos. *Med Pal*. 2007; 14(4):250-6.
2. Elsner F, Centeno C, De Conno F, Ellershaw J, Eychmuller S, Filbet M, Kaasa S, Larkin P. Recommendations of the European Association for Palliative Care for the development of postgraduate curricula leading to certification in Palliative Medicine. Report of the EAPC Task Force on Medical Education. EAPC, Milán 2007. Available on the internet: <http://www.eapcnet.org/download/forTaskforces/PhysiciansTF/EAPC-Curr-PostgraduateMedEdu.pdf> (accessed 2010/03/19).
Translated as: Elsner F, Centeno C, De Conno F, Ellershaw J, Eychmuller S, Filbet M, Kaasa S, Larkin P. Recomendaciones de la Asociación Europea de Cuidados Paliativos (EAPC) para el Desarrollo de la Especialidad en Medicina Paliativa. Informe del Grupo de Trabajo de la EAPC para la Formación Médica. *Med Pal*. 2010. 17(2):103-7.

3. Radbruch L, Payne S, Bercovitch M, Caraceni A, et Al. White Paper on standards and norms for hospice and palliative care in Europe. Recommendations from the European Association for Palliative Care: part 1. *Eur J Palliat Care*. 2009; 16(6):278-89.

Radbruch L, Payne S, Bercovitch M, Caraceni A, et Al. White Paper on standards and norms for hospice and palliative care in Europe. Recommendations from the European Association for Palliative Care: part 2. *Eur J Palliat Care*. 2010; 17(1):22-33.

Both articles translated together: Libro blanco sobre normas de calidad y estándares de cuidados paliativos de la Sociedad Europea de Cuidados Paliativos. Monografías SECPAL. Madrid. 2012.

Initiatives to develop healthcare professional leadership in palliative care:

There is no information available at this time.

Officially recognized medical certification:

- In Spain, there is a very detailed proposal from SECPAL entitled "Área de capacitación específica (ace) y diploma acreditación avanzada (daa) en medicina paliativa" (Specific capacity area and advanced accreditation diploma in Palliative Medicine), Documento definitivo (June 2005).
- Since 2008, the Ministry of Health has developed the basis of legislation for sub-specialization of palliative care in Spain that will be entitled either Specific Training Area or Specific Capacity Area. The process is still ongoing following a change in the Spanish Government (it is currently on the agenda for 2013).
- There are several Master Degrees available in Spain for doctors requiring advanced certification in Palliative Medicine.

Capacity of palliative care workforce training in Universities and Medical Schools:

- There are 41 medical schools in Spain; eight of them provide palliative care as a compulsory component and 13 offer the discipline as an optional component (source: Centeno, C. Palliative Care Undergraduate Education. Oral Presentation).
- Since 2012, there has been a Chair in Palliative Care at the University of Vic (Barcelona); however, there are no full Professors with national academic accreditation.
- There are an estimated three assistant professors (Titular Professors with national academic accreditation).
- There are an estimated five to eight "other professors" (palliative care physicians with a PhD and the academic position of associate professor or other kind of academic accreditation such as contracted professor or a position in a faculty of medicine).
- There are an estimated three to ten "other professors non-medical" (nurses with a PhD or Master Degree with the academic position of associate professor or other kind of academic accreditation such as contracted professor or a position in a faculty or school of nursing).

New Laws about "Death process and Dignity" have been launched in three regions of Spain (Andalucía, Aragón and Navarra). These Laws include the right to receive palliative care for all citizens

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- All essential medications are partially or fully financed by the National Health System.
- No barriers relating to the availability of essential medications have been identified.

Developments/opportunities/barriers relating to the accessibility of essential medications:

- All essential medications are partially or fully financed by the National Health System.
- No barriers relating to the accessibility of essential medications have been identified.

Developments/opportunities/barriers relating to the affordability of essential medications:

No barriers relating to the affordability of essential medications have been identified.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

Some regional governments have identified a number of opioids (not all opioids) as an inefficient form of treatment (as they are too expensive). In this situation, prescribing of these opioids by public team doctors is discouraged (it is not prohibited but there are some barriers to prescribing practices).

Initiatives to promote attitudinal change in relation to 'opiophobia':

There is no information available at this time.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

Such initiatives are not necessary in Spain because access to opioids is free of charge (or relatively cheap).

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- The inclusion of end of life (palliative) care as a right in the list of services provided by the Spanish Public Health System as approved by Organic Law.
- The identification of palliative care as a very important issue in Spanish healthcare policy.

The impact of these policy changes and ways in which they have been important:

- Almost all regional governments in Spain have implemented the new palliative care strategy.
- A number of public palliative care teams (mainly home care teams) have been created throughout the country.

Development of a national palliative care consensus:

- The Consensus adopted by the central (national) administration, regional governments, key stakeholders and the scientific associations, in relation to "Palliative Care Strategy in the National Health Care System" (to promote quality palliative care in Spain). The consensus dates from 2007 and was evaluated in 2010. Regular meetings are held (approximately every six months) to improve the consensus.
- Palliative care clinical guidelines were published by the Ministry of Health in 2008.
- Standards for developing palliative care units were published by the Ministry of Health in 2010.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

As above.

Development of an advocacy framework for integrating palliative care into the health care system:

The working group that meet every six months in the Ministry of Health has the task of developing an advocacy framework for integrating palliative care into the health care system.

Strategies to improve political awareness and government recognition of palliative care:

"Palliative Care Strategy in the National Health Care System" (2007).

The Consensus adopted by the central (national) administration, regional governments, key stakeholders and the scientific associations, in relation to "Palliative Care Strategy in the National Health Care System" (to promote quality palliative care in Spain) was important. The consensus dates from 2007 and was evaluated in 2010

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

- From 2007, the National Health System has provided more than 7,000,000 Euros per year to facilitate education, promotion and research in palliative care. This money has been transferred to regional administrations.
- From 2009, the “Obra Social La Caixa Foundation” has provided in excess of 5,000,000 Euros per year to develop psychosocial teams in palliative care (there are now 30 teams throughout the country).

Involvement with the European Union in relation to hospice and palliative care initiatives:

There was a joint educational programme in palliative care developed by the regions of Alentejo (Portugal) and Extremadura (Spain), financed by the Inter-regional European Union Programme (2005-2006).

Development of initiatives framing palliative care as a ‘human right’:

By law, palliative care has been a basic human right for every Spanish citizen since 2002.

General legislation relating to palliative care:

- Ley 41/2002, de 14 de noviembre. Autonomía del paciente y documentación clínica: “...Artículo 21. El alta del pacient. En caso de no aceptar el tratamiento prescrito, se propondrá al paciente o usuario la firma del alta voluntaria. Si no la firmara, la dirección del centro sanitario, a propuesta del médico responsable, podrá disponer el alta forzosa en las condiciones reguladas por la Ley. El hecho de no aceptar el tratamiento prescrito no dará lugar al alta forzosa cuando existan tratamientos alternativos, aunque tengan carácter paliativo, siempre que los preste el centro sanitario y el paciente acepte recibirlos. Estas circunstancias quedarán debidamente documentadas. ...”
- Ley 16/2003, de 28 de mayo. Cohesión y calidad del Sistema Nacional de Salud: “...Artículo 13. Prestación de atención especializada. La atención especializada comprende actividades asistenciales, diagnósticas, terapéuticas y de rehabilitación y cuidados, así como aquellas de promoción de la salud, educación sanitaria y prevención de la enfermedad, cuya naturaleza aconseja que se realicen en este nivel. La atención especializada garantizará la continuidad de la atención integral al paciente, una vez superadas las posibilidades de la atención primaria y hasta que aquél pueda reintegrarse en dicho nivel. ...”

Published national documents relating to palliative care standards and norms:

- Printed version: Unidades de Cuidados Paliativos. Estándares y Recomendaciones, 2010.
- There are also Evidence-Based Palliative Medicine Guidelines (printed version): Guía de Cuidados Paliativos. Control de Síntomas (online version): <https://www.cgcom.es/sites/default/files/Cuidados%20paliativos.%20control%20de%20sintomas.pdf>

National Plan or Strategy of Palliative Care:

- Estrategia en cuidados paliativos del Sistema Nacional de Salud (2007) y
- Estrategia en cuidados paliativos del Sistema Nacional de Salud: actualización 2010-2014.

National Cancer Control Strategy:

- Estrategia en Cáncer del Sistema Nacional de Salud. 2006
- Estrategia en Cáncer del Sistema Nacional de Salud. Actualización 2010
- Ministerio de Sanidad y Política Social. Estrategia en Cáncer del Sistema Nacional de Salud. Madrid. 2010
- Consult: 05/24/2012. Available at: www.msps.es/organizacion/sns/.../ActualizacionEstrategiaCancer.pdf

National HIV/AIDS Strategy:

Plan Multisectorial frente a la infección VIH y el SIDA. España 2008-2012. Diciembre 2007
Consult: 06/23/2012
Available at: <http://www.msc.es/ciudadanos/enfLesiones/enfTransmisibles/sida/docs/PMS200812.pdf>

National Primary Health Care Strategy:

There is no information available at this time.

Designated policy maker for the delivery of palliative care services:

Antonio Pascual Lorenzo is the designated policy maker for the delivery of palliative care services.

Department of Health specific responsibility for the delivery of palliative care services:

There is no information available at this time.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- Opioids require an additional prescription signed by the prescribing physician (general practitioner or specialist) (<http://www.aemps.gob.es/medicamentosUsoHumano/estupefacientesPsicotropos/home.htm#talonarios>). Strong opioids are available in the pharmacy; their acquisition requires only the additional prescription.
- Pain guidelines: There are many guidelines published on pain management. For example: Porta J, Gómez-Batiste X, Tuca A. Control de Síntomas. Cáncer Avanzado y Terminal. ICO. Barcelona. 2008; Benítez MA, González T. Tratamientos protocolizados en Cuidados Paliativos. CANPAL. Madrid. 2010
- <https://www.cgcom.es/sites/default/files/Cuidados%20paliativos.%20control%20de%20sintomas.pdf>

Funding of palliative care services:

The Spanish National Health System consists of autonomous local health systems that provide all palliative care services free of charge (although there may be a partial payment required for some medications).

From 2007, the National Health System has provided more than 7,000,000 Euros per year to facilitate education, promotion and research in palliative care. This money has been transferred to regional administrations in 2010

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

There has been a change in public awareness of hospice and palliative care following major discussions about end-of life care in Spain during 2011.

Major public discussion, debate or controversy about hospice and palliative care:

There is no information available at this time.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

There is no information available at this time.

Hospice or palliative care 'success' stories:

There is no information available at this time.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is no information available at this time.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

There is no information available at this time.

Most significant issues facing hospice and palliative care in the next three years:

There is no information available at this time.

Implications for palliative care relating to the current economic crisis:

There is no information available at this time.

References

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Herrera E, Rocafort J, De Lima L, Bruera E, García-Peña F, Fernández-Vara G. May 2007. "Regional palliative care program in Extremadura: an effective public health care model in a sparsely populated region". *J Pain Symptom Manage*; 33(5):591-8.

Gómez-Batiste X, Tuca A, Corrales E, Porta-Sales J, Amor M, Espinosa J, Borràs JM, de la Mata I, Castellsagué X; Grupo de Evaluación-SECPAL. June 2006. "Resource consumption and costs of palliative care services in Spain: a multicenter prospective study". *J Pain Symptom Manage*; 31(6):522-32.

Alvarez MP, Agra Y. October 2006. "Systematic review of educational interventions in palliative care for primary care physicians". *Palliat Med*. 2006 Oct;20(7):673-83.

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Gómez-Batiste X; Porta-Sales J; Pascual A; Nabal M; Espinosa J; Paz S; Minguell C; Rodríguez D; Esperalba J; Stjernswärd J; et al.; Department of Health. Palliative Care Advisory. May 2007. "Catalonia WHO palliative care demonstration project at 15 Years (2005)". *Journal of Pain & Symptom Management*; 33 (5): 584-90.

Centeno C, Arnillas P, Hernansanz S, Flores LA, Gomez M, Lopez-Lara F. September 2000. "The reality of palliative care in Spain". *Palliat Med*; 14(5):387-94.

Gomez-Batiste X, Porta J, Tuca A, Corrales E, Madrid F, Trelis J, Fontanals D, Borràs JM, Stjernswärd J, Salva A, Rius E. August 2002. "Spain: the WHO Demonstration Project of Palliative Care Implementation in Catalonia: results at 10 Years (1991-2001)". *J Pain Symptom Manage*; 24(2):239-44.

Centeno C, Hernansanz S, Flores LA, Rubiales AS, Lopez-Lara F. August 2002. "Spain: palliative care programs in Spain, 2000: a national survey". *J Pain Symptom Manage*; 24(2):245-51.

There has been a change in public awareness of hospice and palliative care following major discussions about end-of life care in Spain during 2011

Sweden¹

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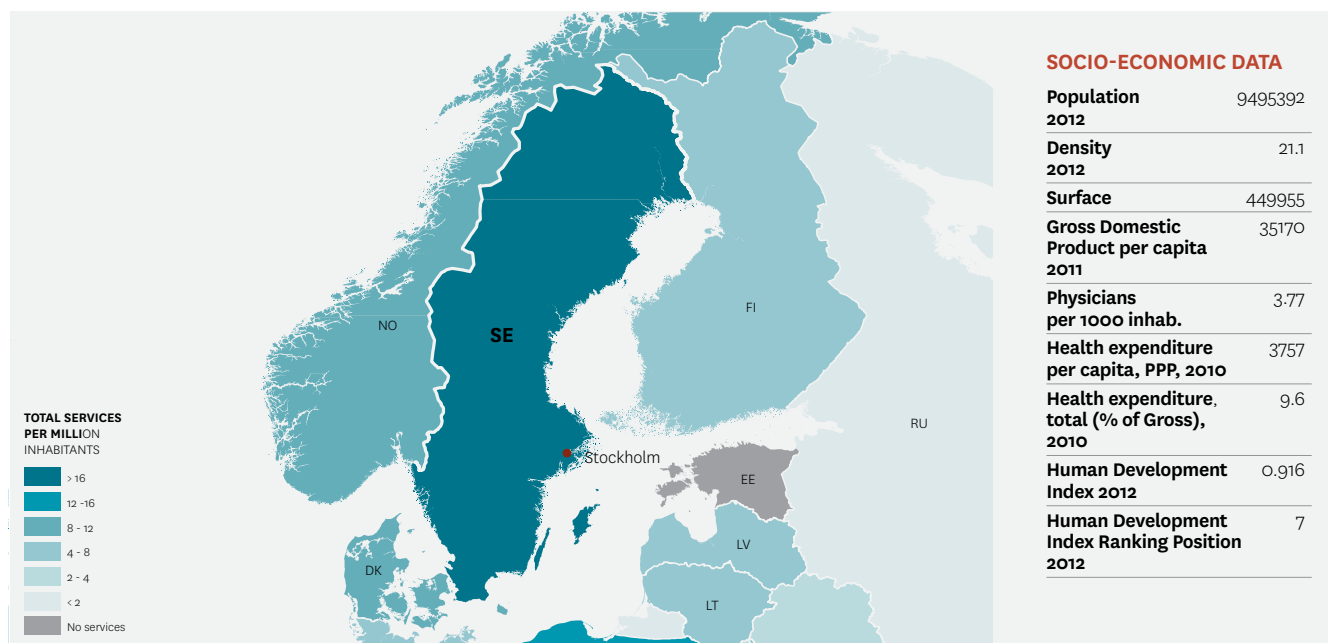
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 25 |
| Hospital palliative care support team | 0 |
| Home palliative care support team | 94 (3158) |
| Mixed palliative care support team | 26 (124) |
| Palliative care units in tertiary hospitals | 19 (214) |
| Palliative care units in non-tertiary hospitals | 8 (49) |
| Inpatient hospice | 11 (123) |
| Day hospice/day care centre | 19 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

Palliativguiden 2010 (Directory of palliative care services in Sweden, 2010).

Additional comments:

There is no additional information available at this time.

Palliative care services for children:

There is no information available at this time.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

- | | |
|-------------|---|
| 2003 | The Swedish Association of Palliative Medicine mark the publication of the Council of Europe (2003) report on palliative care (Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care) at a hearing in Stockholm and through a radio interview. |
| 2004 | The Swedish Association of Palliative Medicine participates in the Council of Europe discussions about euthanasia (the Marty Report) by making a statement against the practice of euthanasia. However, there are some limited initiatives in Sweden that seek the legalization of euthanasia or assisted suicide (mainly in newspaper articles). |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- Increased interest in palliative care among the general public, administrators, professionals and politicians.
- A national cancer strategy and subsequent initiatives at the National Board of Health and Welfare; new national palliative care guidelines; increased financial support and administrative pressure to use the Swedish palliative care quality registry; increased use of the Liverpool Care Pathway.

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: There have been more referrals from hospitals to palliative care.
- Nursing homes: Use of the palliative care quality registry.
- Residential homes for the elderly: Use of the palliative care quality registry.
- Other community settings: Development of specialized palliative care services.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

There has been an expansion *from a focus on cancer patients to address the needs of 'non-cancer' patients.*

Perceived barriers to the development of hospice and palliative care:

- Lack of medical specialization.
- Attitudes of ignorance towards palliative care.
- The decentralized health care system in Sweden makes it difficult to lobby for palliative care.

Perceived opportunities for the development of hospice and palliative care:

- Potential to become a medical speciality.
- Establishment of national guidelines.
- Development of the palliative care quality registry.

Other issues relevant to the development of hospice and palliative care:

There is no information available at this time.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- The Swedish Association for Palliative Medicine (Svensk förening för palliativ medicin - SFPm) was formed in 1997; the association has a website (www.sfp.m.se), and is representative of the whole country.
- The National Council for Palliative Care (Nationella rådet för palliativ vård) was formed in 2004; the council has a website (www.nrpv.se), and is representative of the whole country.

Directory or catalogue of palliative care services:

- Printed version: Palliativguiden (first edition 2008, latest edition 2010).
- Online version: <http://www.nationellaradetforpalliativvard.se/blanketter/publikationer/Palliativguiden%202010/Palliativguiden%202010%20sid%201-18.pdf> (first edition 2008, latest edition 2010).

Congresses, scientific meetings or scientific journals in palliative care:

- There is an annual meeting of the Swedish Association for Palliative Medicine, attended by approximately 100 participants.
- There is a National Conference of Palliative Care held on a biannual basis, and attended by approximately 500 participants.

Palliative care research capacity:

- Research centres include:
 1. Ersta Sköndal högskola (<http://www.esh.se/>)
 2. Stockholms sjukhem (<http://www.stockholmssjukhem.se/>)
 3. Sahlgrenska akademien (<http://www.sahlgrenska.gu.se/>)
- Researchers include:
 1. Peter Strang (peter.strang@ki.se)
 2. Carl Johan Fürst (carljohan.furst@ki.se)
 3. Britt Marie Ternstedt (britt-marie.ternstedt@esh.se)
 4. Joakim Ohlen (joakim.ohlen@fhs.gu.se)
 5. Bertil Axelsson (bertil.axelsson@jll.se)

Palliative care collaboration:

- The Nordic Specialist Course in Palliative Medicine is organised jointly by the National Associations for Palliative Medicine in Sweden, Norway, Denmark, Finland and Iceland.
- Pioneers include: The Swedish Association for Palliative Medicine www.sfp.m.se. Founded in 1997, the Swedish Association for Palliative Medicine has: established a Swedish curriculum in palliative medicine; organised the Nordic Specialist Course in Palliative Medicine; founded the National Council for Palliative Care; developed the national quality register for palliative care; published the first national guidelines for palliative care; taken part in the development of national recommendations for palliative care from the National Board of Health and Welfare; lobbied for palliative medicine to become a medical subspecialty.
- World Hospice and Palliative Care Day was celebrated in Lund, Sweden (8th October 2011).

Worldwide palliative care alliance level of development:

4A (Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision).

There have been more referrals from hospitals to palliative care, and specialized palliative care services have developed in community settings. There has been an increased focus on the needs of 'non-cancer' patients

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:
There have been several local palliative care education and training initiatives.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: There have been several local palliative care education and training initiatives.
- Nursing: There have been several local palliative care education and training initiatives.
- Social work: There have been several local palliative care education and training initiatives.
- Other professions: There have been several local palliative care education and training initiatives.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: The Diploma in Palliative Medicine is endorsed by SFPM.
- Nursing: The Diploma in Palliative Nursing is endorsed by SFPM.
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Translation of palliative care documents or other materials:

There is no information available at this time.

Initiatives to develop healthcare professional leadership in palliative care:

There is no information available at this time.

Officially recognized medical certification:

- The Diploma in Palliative Medicine has been accredited by the Swedish Association for Palliative Medicine since 2006 (62 healthcare professionals have been accredited in this way)
- In Sweden, accreditation is in process at the National Board of Health and Welfare which has commenced a review of medical specialties in the country. It is anticipated that Palliative Medicine will become a medical sub-specialty through this process in 2013. There is currently a Nordic Specialist Course in Palliative Medicine (NSCPM); a joint venture between Palliative Medicine Associations in five Nordic countries. The course is a theoretical specialist training course consisting of six (one-week) modules over the course of two years (<http://www.nscpm.org/>); a number of healthcare professionals from Sweden have completed the course.

Capacity of palliative care workforce training in Universities and Medical Schools:

- Sweden has seven medical schools, of which an estimated three provide palliative care as an optional component (based on personal experience).
- There is one full Professor of Palliative Medicine, and an estimated four “other professors” (based on personal experience).

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

There is no information available at this time.

Developments/opportunities/barriers relating to the accessibility of essential medications:

There is no information available at this time.

Developments/opportunities/barriers relating to the affordability of essential medications:

There is no information available at this time.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to ‘opiophobia’:

There is no information available at this time.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

There has been increased interest in palliative care among the general public, administrators and healthcare professionals and politicians. The government has provided increased financial support for a number of palliative care initiatives

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

There is no information available at this time.

The impact of these policy changes and ways in which they have been important:

There is no information available at this time.

Development of a national palliative care consensus:

Development of the national guidelines on palliative care.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

A large number of small but significant meetings to develop palliative care strategies have been held on different levels.

Development of an advocacy framework for integrating palliative care into the health care system:

Palliative care is already integrated into the health care system.

Strategies to improve political awareness and government recognition of palliative care:

There is no information available at this time.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

There is no information available at this time.

Involvement with the European Union in relation to hospice and palliative care initiatives:

EU 7th framework project "OPCARE g" and various other research projects.

Development of initiatives framing palliative care as a 'human right':

There have been no specific initiatives framing palliative care as a 'human right'.

General legislation relating to palliative care:

There is no information available at this time.

Published national documents relating to palliative care standards and norms:

- Printed version: Nationellt vårdprogram för palliativ vård (National guidelines for palliative care) January 2012.
- Online version: in process.

National Plan or Strategy of Palliative Care:

There is no information available at this time.

National Cancer Control Strategy:

En nationell cancerstrategi för framtiden SOU 2009:11 (<http://www.regeringen.se/sb/d/108/a/120976>).

National HIV/AIDS Strategy:

There is a National HIV/AIDS Strategy but it contains no reference to palliative care provision.

National Primary Health Care Strategy:

There is no information available at this time.

Designated policy maker for the delivery of palliative care services:

There is no information available at this time.

Department of Health specific responsibility for the delivery of palliative care services:

Regional governments have the responsibility for providing palliative care services.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

- Svenska Palliativregistret (www.palliativ.se)
- The Swedish national quality register has the aim of registering the care of all dying people in Sweden. Every year approximately 90,000 people die in Sweden and currently about 35,000 people are registered annually.

Opioid legislation/Pain guidelines:

- All medical doctors can prescribe opioids. All hospitals and pharmacies can dispense opioids on prescription.
- Printed pain guidelines: The Swedish Medical Products Agency published pain guidelines in December 2010.
Online version: <http://www.lakemedelsverket.se/english/>.

Funding of palliative care services:

There may be partial payment required for palliative care consultation, hospitalisation and medications.

A National Cancer Strategy and initiatives at the National Board of Health and Welfare have been introduced; new palliative care guidelines have been developed, there is a Palliative Care Quality Registry, and use of the Liverpool Care Pathway has increased

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

There has been a positive change in public awareness and perception of hospice and palliative care.

Major public discussion, debate or controversy about hospice and palliative care:

There have been many discussions about hospice and palliative care in all forms of mass media.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

There have been several initiatives that seek to broaden awareness and understanding of hospice and palliative care.

Hospice or palliative care 'success' stories:

There have been several hospice or palliative care 'success' stories.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There is an ongoing debate in Swedish society in relation to euthanasia or assisted dying.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

There is every reason to be "very optimistic" about the future of hospice and palliative care in Sweden.

Most significant issues facing hospice and palliative care in the next three years:

- The recognition of palliative care as a medical specialty.
- Development and use of national quality indicators and guidelines.
- Increasing registration of deaths in the national quality register.
- Inclusion of palliative care in the work of the regional cancer centres to improve the provision of care.
- Development of general palliative care initiatives (leadership, competency, teamwork, etc.).

Implications for palliative care relating to the current economic crisis:

- There are a increasing number of elderly people in Swedish society (and decreasing financial resources).
- There is a need to increase understanding about the ways in which palliative care can improve the quality of care provided (and demonstrate how it can be used to reduce costs).

There has been a positive change in public awareness and perception of hospice and palliative care

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Switzerland¹

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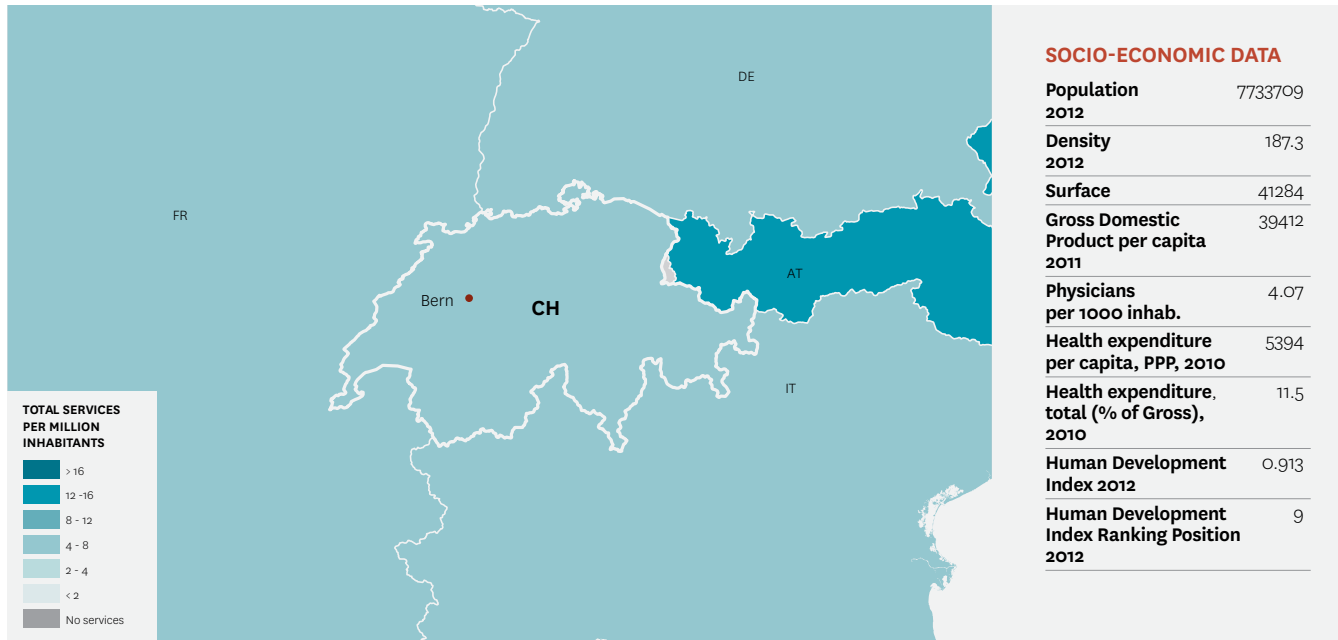
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 1 |
| Hospital palliative care support team | 14 |
| Home palliative care support team | 19 |
| Mixed palliative care support team | 3 |
| Palliative care units in tertiary hospitals | 14 (151) |
| Palliative care units in non-tertiary hospitals | 5 (70) |
| Inpatient hospice | 6 (55) |
| Day hospice/day care centre | 2 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Palliative Care directory, 2nd edition 2010/national survey
- http://www.palliative.ch/fileadmin/user_upload/palliative/fachwelt/H_%20Downloads/Palliative_Directory_2011.pdf

Additional comments:

There is no information available at this time.

Palliative care services for children:

There is one paediatric hospital palliative care support team, one paediatric home palliative care support team, one paediatric mixed palliative care support team and one paediatric palliative care unit in a tertiary hospital (six beds).

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|------------------|---|
| 1995-2005 | The action plan “hospitals without pain” is produced between the Swiss Cancer League and the Association created by Prof. Charles-Henri Rapin “Ensemble contre la douleur” (‘together against pain’). |
| 2001 | The Swiss Society for Palliative Care holds a consensus day in collaboration with the Swiss Cancer League on the development of palliative care in Switzerland. |
| 2001 | The Manifeste de Fribourg is presented and approved by 600 health professionals, politicians and representatives of insurance companies. The document sets out the basis for palliative care development in “5 years – 5 goals”. The Manifeste de Fribourg is considered as a baseline document and is to be used in 2006 to assess the previous five years’ development. |
| 2001 | The national boards of the two most important health profession associations, the Swiss Association of Nurses (ASI –SBK) and the Federation of Swiss Physicians (FMH) publish a position paper on “End of life care.” The paper is published in several professional reviews, representing a collective group of approximately 53,000 professionals. |
| 2002 | The Swiss Education Committee publishes recommendations for palliative care education. |
| 2003 | The Swiss Society for Palliative Care (in collaboration with the Swiss Cancer League) holds an annual day (November 23rd) in Fribourg to mark the publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organisation of palliative care). |
| 2004 | The Swiss Education Committee work on a procedure for accrediting palliative care courses at the national level (according to national recommendations). |
| 2005 | A Chair in Palliative Medicine is established in Lausanne (the French speaking part of Switzerland). Professor Jose Pereira is chosen to be the first Professor of Palliative Medicine, working as an academic Professor for the Universities of Lausanne and Geneva, and as chief doctor of the palliative care division CHUV Lausanne. |
| 2005 | The Quality Group initiates a participatory process with palliative care teams. The aim is to develop a palliative care quality label by 2008. |
| 2005 | The Swiss Research Group is created. |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- The need for action in the area of palliative care has been recognised by the political authorities. The Head of the Federal Department of Home Affairs (FDHA) commissioned the Federal Office for Public Health (FOPH) in January 2008 to clarify the situation concerning palliative care in Switzerland. The clarification clearly showed the inadequate establishment of palliative care in the public health sector and the urgent need to raise awareness both among health professionals and the general public.
- Consequently, in the summer of 2008, the Head of the FDHA declared the promotion of palliative care to be a priority of his Department. Mandated by the FDHA, the FOPH entered into discussions with the Swiss Conference of the Cantonal Ministers of Public Health, which also viewed the promotion of palliative care as an important public health issue.
- At the end of October 2008, the FDHA and the Swiss Conference of the Cantonal Ministers of Public Health jointly set up a National Funding Committee “Palliative Care” consisting of a steering committee and four expert-working groups on the themes “Care and financing”, “Information”, “Training” and “Research”. Under the direction of the FOPH and the Swiss Conference of the Cantonal Ministers of Public Health, 80 experts prepared a report on the need for action in the field of palliative care in Switzerland (January to June 2009).
- Based on this report and further studies, the FOPH and the Swiss Conference of the Cantonal Ministers of Public Health jointly prepared the “National Strategy for Palliative Care 2010-2012”. In this strategy, the Confederation and Cantons (in conjunction with key stakeholders in the spheres of healthcare, social care, training and research) set the main objective of establishing palliative care in Switzerland. The strategy was adopted on 22nd October 2009 from the discussion on National Health Policy. The implementation of the strategy commenced in January 2010 (www.bag.admin.ch/palliativecare).

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: Surveys from 2008 and 2011 demonstrate the situation relating to specialist palliative care. The number of palliative care units and clinics has increased since 2008. The number of specialist palliative care beds is about one-third higher in 2011 than in 2008 (but is still only 50% of the number recommended by EAPC). There are many regions without any palliative care provision. In the context of the National Strategy of Palliative Care, great effort was made to develop the quality and standardization of palliative care. Palliative care (the Swiss Association for Palliative Care), developed quality criteria for different healthcare settings. Palliative care units and clinics can apply for an audit and are awarded a label of quality in palliative care if they meet the required criteria. Supportive palliative care teams have been established in about 5% of hospitals in Switzerland.
- Nursing homes: There are only a few nursing homes in Switzerland offering specialist palliative care. There are also quality criteria for palliative care in long-term settings such as nursing homes.
- Residential homes for the elderly: The Association of Residential Homes (Curaviva) commenced initiatives for in-house palliative care training for their healthcare professionals.
- Other community settings: Home care has been improved by mobile palliative care teams in some cantons (established in approximately one-quarter of all cantons).

Expansion from a focus on cancer patients to address the needs of ‘non-cancer’ patients:

The national strategy explicitly addresses all chronically ill and dying people; geriatrics has been a part of palliative care since it began to be developed. The national strategy focuses on chronic diseases (but is lacking in the areas of heart or lung disease).

Perceived barriers to the development of hospice and palliative care:

- Health policy: Switzerland is divided into 26 cantons which function like republics in an autonomous way, each of them possessing its own health law. There are, therefore, 26 health policies (which makes it difficult to implement a National Palliative Care Strategy).
- Financing: There are different financing modalities for specialist units, mobile teams, hospitals, nursing and residential homes and home care and also different responsibilities (Confederation, cantons and communities). So for each setting, the difficulties must be identified and discussed with the institutions concerned.
- Lack of awareness of hospice and palliative care.
- Lack of education and training in palliative care.

Perceived opportunities for the development of hospice and palliative care:

- Growing political awareness about the importance of palliative care (and increased support from political authorities).
- Demographic development of the Swiss population with an increase in deaths by 50% in the next 40 years.
- The discussion about physician-assisted suicide has also forced politicians to discuss palliative care.

Other issues relevant to the development of hospice and palliative care:

- In 2010, the national research programme "End of life (NFP 67)" commenced. The purpose of NRP 67 is to gain knowledge useful to guiding decisions and practices at the end of life and to make this knowledge available to decision-makers in the health care system, as well as to politicians and professionals involved in the care of persons at the end of life. This knowledge is specifically intended to:
 - Enhance the assessment of medical care received by individuals at the end of life and, in particular, to identify gaps or problems in the provision of care;
 - Provide those affected (and healthcare professionals) with a better basis for appropriate decisions and processes;
 - Identify prerequisites for a just and dignified provision of care at the end of life, establish legal regulations as required, and reflect on the ethical implications;
 - Facilitate the understanding of social developments and the prediction of future developments;
 - Strengthen scientific competencies in the area of end of life and palliative care research.
- The NRP 67 has an overall budget of CHF 15 million at its disposal. The time-frame for the research is five years.
<http://www.nfp67.ch/E/Pages/home.aspx> .

Vitality

THE VITALITY OF PALLIATIVE CARE**National Associations of Palliative Care:**

- The association Palliative.ch (palliative.ch Schweizerische Gesellschaft für Palliative Medizin, Pflege und Begleitung) was formed in 1986; the association has a website (www.palliative.ch), and is representative of the whole country (although it is organized via regional sections).

Directory or catalogue of palliative care services:

- Printed Version: Palliative Care Directory Switzerland (first edition December 2008, latest edition December 2010).
- Online version:
http://www.palliative.ch/fileadmin/user_upload/palliative/fachwelt/H_%20Downloads/Palliative_Directory_2011.pdf
 (first edition December 2008, latest edition December 2010)

Congresses, scientific meetings or scientific journals in palliative care:

- There is a National Palliative Care Conference held annually and attended by approximately 500-600 participants.
- There are also various palliative care conferences held within the regional sections.
- The journal *palliative.ch* is published four times per year (edited in German, French and Italian).

Palliative care research capacity:

Research centres include:

- Plateforme latine de la recherche en soins palliatifs (French and Italian-speaking platform): <http://www.plrsp.ch/>
- Forschungsplattform Palliative Care Deutschschweiz (German-speaking platform): www.palliative.ch

Palliative care collaboration:

- There is a plan to create a National Institute for Palliative Care with the aim of combining the efforts of the national government, the regional governments and palliative.ch.
- There is palliative care collaboration within the EAPC research network and collaboration within EU- research grants (EPCRC via F. Strasser; OPCAREg - IORC via S. Eychmueller; Euro- Sentinel network via S. Pautex).
- Palliative.ch - the national association - has pioneered palliative care in Switzerland for many years - which is surprising due to the regional/ cantonal structure/ paradigm of the country.
- Each year, World Hospice and Palliative Care Day is celebrated and promoted by palliative.ch and its regional sections (provision of information, concerts, publications in the media etc.)

Worldwide palliative care alliance level of development:

4A (Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision).

The need for action in relation to palliative care has been recognised; in 2008, the Head of the Federal Department of Home Affairs (FDHA) commissioned the Federal Office for Public Health (FOPH) to clarify the palliative care situation in Switzerland

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- Various ideas prevail in regard to the expertise required for palliative care. In basic training, the fundamentals exist to enable all health professionals to progress to the secondary level stage II as well as to the tertiary level stage A and B; palliative care can be integrated into these courses. However, the commitment to and the implementation of these guidelines vary to a great degree.
- In further education and continuous education there are gaps, principally in the outpatient area and in long-term care. For example, specialised knowledge about palliative care among general practitioners (who care for patients in retirement homes and nursing homes) is often insufficient. Problems arise with diagnoses, communication and the relief of pain.
- Existing training courses are confusing, poorly coordinated and not systematically checked in regard to their quality. The offer of inter-professional training is very sparse, and there are few individual initiatives in the field of further education (nursing and human medicine).
- The National Strategy on Palliative Care has defined a field of action "training, further education and continuous education." Its overall objective is for specialists and volunteers who are active in palliative care to be provided with the required appropriate level of expertise.
- A common educational concept for palliative care needs to be developed for all occupational groups.
- Palliative care as an integral component of the training, further education and continuous education of the university medical professions and of the non-university health and social professions as well as for other relevant occupational groups needs to be promoted.
- Volunteers should be provided with expertise in palliative care and receive the required support to accomplish their tasks.
- The educational concept for palliative care has been elaborated and will be adopted in March 2012.
- An expert group of palliative care has developed catalogues of competencies for Level B and C for physicians, nurses and psychosocial professionals.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Palliative care is now a topic in the list of learning goals for medical professionals; in 2011 (for the first time) 5% of questions in the final examination of medical students were related to issues of palliative care.
- Nursing: Palliative Care is now included in all nursing education programs
- Social work: To date, there are no palliative care education initiatives established in this area.
- Other professions: To date, there are no palliative care education initiatives established in this area.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: Palliative care is included as a topic in the curriculum of geriatrics and oncology. For the other specialities (including family physicians), discussions have started as to how palliative care could be included in the curriculum. Two or three congresses each year for family doctors include seminars on palliative care. There is a Level A2-course for doctors only, several multi-professional courses at Level A and B and one Course at Level C (MAS).
- Nursing: There are several nursing education classes at Level A and B, multi-professional courses at Level A and B and one course at Level C (MAS).
- Social work: There are some palliative care seminars, but overall progress in this area is poor.
- Other professions: There are some palliative care courses for physiotherapists and pastors and one course in psycho-oncology that includes the topic of palliative care.

Translation of palliative care documents or other materials:

- Papers relating to the national strategy have been translated in all three national languages (German, French and Italian).
- The National Strategy on Palliative Care (2010–2012) is available in English
- National Guidelines on Palliative Care are available in English (March 2012)
- The EAPC White Paper of Standards and Norms in Palliative Care has been translated in German.
- Medical-ethical guidelines and recommendations for palliative care have been elaborated and published by the Swiss Academy of Medical Sciences (translated in French, Italian and English).

Initiatives to develop healthcare professional leadership in palliative care:

There is one faculty in Lausanne that has developed healthcare professional leadership in palliative care, and the University hospitals of Bern and Zurich have opened palliative care wards. A curriculum for palliative care specialists is in progress, but there is a lot of opposition by the medical associations. Universities for applied science have developed postgraduate curricula for nurses.

Officially recognized medical certification:

- Switzerland expects Palliative Medicine to become a sub-specialty by 2016.
- Other forms of accreditation include various training courses:
 - basic courses (40 hours) for all healthcare professionals.
 - a two-year inter-professional "specialist" diploma course (not yet officially accredited).
 - Master degree of advanced studies (MAS) in palliative care.

Capacity of palliative care workforce training in Universities and Medical Schools:

- Switzerland has five medical schools, all five of them providing palliative care as an obligatory component (the national law for academic training in health care professions stipulates that regular training in palliative care is mandatory for all medical students).
- There is one full Professor of Palliative Medicine (in Lausanne), two "other professors" (one within oncology, one within geriatrics), and within the category of "assistant professors non-medical", there are an estimated three nursing professors at academic schools ("Fachhochschulen").

The FDHA declared palliative care to be a priority of the Department. Mandated by the FDHA, the FOPH entered into discussions with the Swiss Conference of the Cantonal Ministers of Public Health and a National Funding Committee was established

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

All essential medications are available in Switzerland.

Developments/opportunities/barriers relating to the accessibility of essential medications:

All essential medications are accessible in Switzerland.

Developments/opportunities/barriers relating to the affordability of essential medications:

All essential medications are reimbursed by basic health insurance.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

There is no information available at this time.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

Economically disadvantaged persons have the same access to opioid medication as the rest of the population.

Initiatives that consider access to essential medication as a legal and human right:

There is no information available at this time.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- Legal changes: In 2011, fifteen cantons had the provision of palliative care included in their health laws.
- Health policy: The confederation has recognised the need for action in the area of palliative care and, together with the Swiss Conference of the Cantonal Ministers of Public Health, established a National Strategy for Palliative Care (2010-2012). Nine cantons have adopted a cantonal concept or strategy to promote palliative care in their area. Five cantons are elaborating or planning to elaborate a cantonal concept or strategy to promote palliative care in their area.

The impact of these policy changes and ways in which they have been important:

The mandate to promote palliative care came from the Head of the Federal Department of Home Affairs (FDHA), a member of the federal council which is the executive authority in Switzerland.

Development of a national palliative care consensus:

- In 2006, the medical-ethical guidelines and recommendations for palliative care were elaborated and published by the Swiss Academy of Medical Sciences. <http://www.samw.ch/en/Ethics/Guidelines/Currently-valid-guidelines.html>
- The National Guidelines on Palliative Care were elaborated and adopted on October 21st 2010. They constitute a broad consensus about the definition of palliative care, its principles, values, target groups, settings of care and providers. The guidelines have been distributed to a large number of institutions and individuals (the guidelines are in constant demand).

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

- In October 2008, the Federal Department of Home Affairs (FDHA) and the Swiss Conference of the Cantonal Ministers of Public Health set up a National Funding Committee "Palliative Care" consisting of a steering committee and four expert-working groups on the themes "Care and financing", "Information", "Training" and "Research".
- Under the direction of the Federal Office for Public Health (FOPH) and the Swiss Conference of the Cantonal Ministers of Public Health, 80 experts prepared a report on the need for action in the field of palliative care in Switzerland (January to June 2009). On 22nd October 2009, the FDHA and Swiss Conference of the Cantonal Ministers of Public Health adopted the National Strategy for Palliative Care (2010-2012). In Spring 2010, a hearing was held with key stakeholders and policy makers to discuss the National Guidelines on Palliative Care. On 20th January 2012, the first meeting took place between representatives of all cantons, discussing questions of financing and structuring of palliative care. In 2009 and 2011 a national palliative care congress took place in collaboration with the Federal Office for Public Health (FOPH) and palliative.ch.

In 2009, a report was prepared on the need for action in the field of palliative care in Switzerland. Based on this report and further studies the "National Strategy for Palliative Care 2010-2012" was launched

Development of an advocacy framework for integrating palliative care into the health care system:

A major objective of the National Strategy for Palliative Care is that the Confederation and Cantons will collaborate with key stakeholders to integrate palliative care in the field of public health and other areas.

Strategies to improve political awareness and government recognition of palliative care:

The task of developing palliative care in Switzerland in 2008 was a “top-down” initiative. This was the result of several initiatives by palliative care such as repeated visits to the Federal Office for Public Health (FOPH) and contacts with politicians over a number of years. In parallel with national contact initiatives, regional networks of palliative care in the cantons contacted their local governments.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

- Since 2010, the Confederation has funded the implementation of the National Strategy on Palliative Care with approximately 700,000,000 CHF per year. Some of the 26 cantons are also funding different projects to develop palliative care.
- The Swiss Cancer League also fund a number of palliative care projects.

Involvement with the European Union in relation to hospice and palliative care initiatives:

There are some research projects (for example, OPCARE 9) which involve collaboration between Swiss institutions and the EU.

Development of initiatives framing palliative care as a ‘human right’:

There have been no such national initiatives. Some cantons have included the right to adequate treatment and end-of-life care in their health laws.

General legislation relating to palliative care:

Legislation is in process: currently, palliative care is only included in the law on academic education for healthcare professionals (a more thorough inclusion of palliative care in general legislation is expected soon).

Published national documents relating to palliative care standards and norms:

- Schweizerische Gesellschaft für Palliative Medizin, Pflege und Begleitung “palliative care” (2001).
- Grundsätze und Richtlinien für Palliative Medizin, Pflege und Begleitung in der Schweiz, Schweizerische Gesellschaft für Palliative Medizin, Pflege und Begleitung “palliative care” (2010).
- Versorgungsstrukturen für spezialisierte Palliative Care Schweiz (first edition 2001, currently under revision).
- Online via www.palliative.ch (in German only).
- http://www.palliative.ch/fileadmin/user_upload/palliative/fachwelt/E_Standards/E_g_1_Standards_Palliative_Medizin_Pflege_Begleitung.pdf (first edition 2001, currently under revision).

National Plan or Strategy of Palliative Care:

“National Strategy of Palliative Care (2010 – 2012)”

German: http://www.palliative.ch/fileadmin/user_upload/palliative/publikum/2_PalliativeCare/2_7%20Kurzversion_Nationale_Strategie_Palliative_Care_DE.pdf
 English (summary): <http://www.bag.admin.ch/themen/medizin/06082/10907/index.html?lang=de>

National Cancer Control Strategy:

- National Cancer Program (2010- 2015)
- Palliative care is an integral part of comprehensive cancer care
- Short version in English: http://www2.oncosuisse.ch/pdf/NKP_2011-2015_Kurzversion_en.pdf

National HIV/AIDS Strategy:

There has been a National HIV/AIDS Strategy since 1995, but palliative care is not an integral part of this document.

National Primary Health Care Strategy:

There is no information available at this time.

Designated policy maker for the delivery of palliative care services:

- There is one central program leader at the national level within the Ministry of Health (Bundesamt für Gesundheit - BAG).
- There are various program leaders (part-time) within the cantonal governments.

Department of Health specific responsibility for the delivery of palliative care services:

As above.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

- The Swiss Association for Palliative Care has edited a series of criteria for quality in various care settings - mainly specialist palliative care, but also primary palliative care in nursing homes (qualite palliative); the association offers health service accreditation through external audits (“table palliative care Switzerland”)
- (<http://www.palliative.ch/index.php?id=127>)

Opioid legislation/Pain guidelines:

- Opioids are available on a special prescription (“Betäubungsmittelrezept”) and can be prescribed by any doctor; they are available from any pharmacy, hospital or private practice dispenser.
- Pain guidelines:
online www.pain.ch; www.palliative.ch (Bigorio recommendations).

Funding of palliative care services:

- There is partial payment required for palliative care consultation (10% of total cost); full payment required for palliative care hospitalisation (depending on the service/ hospital); and partial payment required for palliative care medications (10% of total cost)
- Charitable donations from a number of foundations support many institutions (inpatient and mobile services). Community networks rely on sponsoring/private funding - these include nursing homes (mainly funded by private money - only a small part is paid for by health insurance)
- The research program on “end of life research” (Program 67) was funded by the Swiss National Research Fund (SNF)
- Some cantonal development programs in Vaud, Ticino, Thurgau, and Graubünden have received private funding.

Since 2010, the Confederation has funded the implementation of the National Strategy on Palliative Care with approximately 700,000,000 CHF per year. Some of the 26 cantons are also funding different projects to develop palliative care

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

Public awareness of palliative care has increased slightly (awareness in the French-speaking part of Switzerland is better than in the German-speaking part of the country). There are a lot of local information events to improve awareness.

Major public discussion, debate or controversy about hospice and palliative care:

There has been major public discussion about assisted suicide which is authorized in Switzerland on condition that it is not provided under "egoistic motivation". In 2011, the Swiss government proposed either to forbid it completely or to adapt the law. Both proposals were rejected in a public consultation, so the federal council decided that the legal foundation should not be changed (and to promote palliative care instead). In the context of these public discussions, palliative care received some marginal attention. There has never been a major public discussion about palliative care.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

- The National Strategy on Palliative Care has the objective to increase public awareness and understanding of palliative care. The concept of communication was elaborated and the central messages about palliative care were defined. The website www.palliative.ch has been overhauled and is now a comprehensive information portal on palliative care for the general public and experts. An information brochure on palliative care for the general public has been developed and distributed in 11 of 26 cantons. Two cantons have developed their own brochures.
- Some articles have been published in newspapers and magazines, but it is difficult to gain the attention of the media in relation to palliative care.

Hospice or palliative care 'success' stories:

- In the canton of Thurgau, there was a petition for a referendum, initiated by a group of inhabitants, which lead to a cantonal strategy for the development of palliative care.
- The national strategy is a success because it has moved the issue of palliative care from the level of a few interested professionals to the level of a national political topic.

Initiatives seeking the legalisation of euthanasia or assisted dying:

- Press Release of The Federal Council, 29.06.2011 (English): <http://www.ejpd.admin.ch/content/ejpd/en/home/dokumentation/mi/2011/2011-06-29.html>
- More information about euthanasia in Switzerland (English): http://www.ejpd.admin.ch/content/ejpd/en/home/themen/gesellschaft/ref_gesetzgebung/ref_sterbehilfe.html

The national strategy is a success because it has moved the issue of palliative care from the level of a few interested professionals to the level of a national political topic

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

- In 2012, the Federal Department of Home Affairs (FDHA) and the Swiss Conference of the Cantonal Ministers of Public Health will decide whether the National Strategy on Palliative Care (2010–2012) will be prolonged for another three years.
- In most cantons there has been new planning and definition of duties for all hospitals. Palliative care has been developed in most cantons (it is hoped that more palliative care services will result).

Most significant issues facing hospice and palliative care in the next three years:

One significant issue is how to implement the basic concepts that have been elaborated during the last few years in each canton's health policy. The financing of palliative care in all settings must be clarified. There must be a greater effort to integrate a palliative care approach in settings not specialised in the discipline (general practitioners, general hospitals, nursing homes, home care). Palliative care aims to be a leader in all questions of quality development, research and education.

Implications for palliative care relating to the current economic crisis:

In a period of economic crisis it is difficult to establish new palliative care services. The challenge will be to demonstrate that a broad network of palliative care services can lower healthcare costs by avoiding unnecessary hospitalisation.

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Turkey¹

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 50 |
| Home palliative care support team | 0 |
| Mixed palliative care support team | 10 |
| Palliative care units in tertiary hospitals | 5 |
| Palliative care units in non-tertiary hospitals | 10 |
| Inpatient hospice | 10 |
| Day hospice/day care centre | 0 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

- Symposiums about palliative care in Turkey.
- Komurcu S. Current Status of Palliative Care in Turkey. J Pediatr Hematol Oncol 2011;33:S78-S80
- Presentations from the Ministry of Health

Additional comments:

- There are over 500 homecare teams in Turkey but these are primary care teams and not specific palliative care teams.
- The services detailed above are not separate palliative care units but are incorporated within oncology, neurology, and algology clinics.
- There are no community-based day care centers (but there may be several private centers).
- Within the Ministerial National Plan there are 250 centres to be developed by 2017 (not specifically palliative care centres).

Palliative care services for children:

All palliative care services cover both children and adults.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

- | | |
|-------------|---|
| 1999 | The Subgroup for Supportive Care in Turkish Oncology is formed, comprising of 45 members (medical/radiation oncologists) from 18 different centres. |
| 2004 | The Subgroup for Supportive Care in Turkish Oncology marks the publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organisation of palliative care) by translating the report into Turkish and distributing it to medical centres, the Ministry of Health and other places related to the organization of palliative care. |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

Since the early 1990s, there has been an increasing awareness of the need to develop a national palliative care program (NPCP) in Turkey that includes not only pain relief and symptom control but also considers psychosocial needs in the provision of end-of-life care for patients and their families.

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: An action plan for implementing the NPCP has been prepared. It is anticipated that some palliative care units will be operational in hospitals by 2014.
- Nursing homes: Not much progress
- Residential homes for the elderly: Not much progress
- Other community settings: Nearly 500 home-based teams have provided some form of palliative care throughout Turkey since 2009 s).

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

The NPCP covers all chronic diseases including cancer, stroke, HIV/AIDS etc.

Perceived barriers to the development of hospice and palliative care:

- Lack of awareness about palliative care amongst health and social care personnel.
- Absence of trained health-care personnel.
- Lack of regulations on palliative care (to be published soon).

Perceived opportunities for the development of hospice and palliative care:

- Home care units have expanded throughout the country.
- The Turkish family is a good source of providing care for patients.
- An action plan relating to the NPCP has been recently prepared by the Ministry of Health.

Other issues relevant to the development of hospice and palliative care:

- Educating the community to demand modern palliative care.
- Reimbursement issues relating to the provision of home-based palliative care.

There has been increasing awareness of the need to develop a National Palliative Care Program (NPCP) in Turkey and an Action Plan for implementing the NPCP has been prepared. Some palliative care units will be operational in hospitals by 2014

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- The Turkish Oncology Association, Subgroup for Supportive Care (Turk onkoloji Dernegi, Destek Tedaviler Calisma Grubu) was formed in 1998; the association has a website (<http://togd.net/>) and is representative of the whole country.
- The Palliative Care Association (Palliative Bakim Dernegi) was formed in 2007; the association has a website (www.palyatifbakim.org/) and is representative of the whole country.

Directory or catalogue of palliative care services:

There is no information available at this time.

Congresses, scientific meetings or scientific journals in palliative care:

There is no information available at this time.

Palliative care research capacity:

There is no information available at this time.

Palliative care collaboration:

The Turkish Oncology Association, Subgroup for Supportive Care arranged the first meetings specifically relating to palliative care, and the first post-graduate education initiatives in the field of oncology were provided by this group.

Worldwide palliative care alliance level of development:

3A (Isolated palliative care provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- The concept of palliative care has improved and been disseminated slowly throughout Turkey; however, the development of methods for pain management has improved at a much faster rate. Some pain specialists and oncologists have recognized the need for palliative care services, and a number of doctors have sought palliative medicine training overseas and then returned to Turkey to encourage training and development in palliative care in their own units. The Subgroup for Supportive Care in Cancer (SSCC) in the Turkish Oncology Group was formed in 1999, and consisted of 45 members (medical/radiation oncologists) from 18 different centers. Some oncologists organized several meetings and studies to increase the awareness of health-care professionals about supportive care for patients with cancer, and other end-of-life care issues (communication, etc). Turkey joined the Middle East Cancer Consortium (MECC) in June 2004. MECC is funded by the National Cancer Institute, and supports six member countries to develop a cancer registry, increase cancer awareness, and reduce the burden of the disease in the Middle East. MECC organizes conferences for healthcare professionals and supports initiatives to develop palliative care in the region.

- There were no national guidelines or government support for palliative care until 2008 in Turkey. Some initiatives, driven by the Ministry of Health, Cancer Control Department, and members of several organizations including the Turkish Oncology Group, Palliative Care Organization, Medical Oncology Organization, and Association of Pain, have involved setting up a palliative care committee to undertake initiatives in Turkish universities; palliative care leaders from the World Health Organization have been invited to participate in these initiatives. Since 2009, the Palliative Medicine Committee has held many meetings with the Ministry of Health, organized conferences, and prepared a palliative care action plan. Recently, the Ministry of Health and the Palliative Medicine Committee prepared the palliative care education program for all healthcare professionals.
- New training of family physicians (n=23,000) will commence via the internet in 2013 (this may include palliative care); Hacettepe Oncology Institute (in conjunction with the Ministry of Health will start “train the trainers” courses in 2013, which will be followed by local training covering thousands of nurses, doctors and other healthcare professionals (certified by the Ministry of Health upon completion).

Specific developments in under-graduate palliative care education initiatives:

- Medicine: Hospice and palliative care education has been included in the curriculum of the School of Medicine since 2006.
- Nursing: Palliative care education has been included in Nursing School programs since 2001.
- Social work: Palliative care is not included in the undergraduate social work curriculum.
- Other professions: There are some palliative care programs included in the dietitian and psychology education courses.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: There are some postgraduate courses and symposiums.
- Nursing: There are some postgraduate courses and symposiums.
- Social work: There is no information available at this time.
- Other professions: There are some postgraduate courses and symposiums.

Translation of palliative care documents or other materials:

- The European Society for Medical Oncology (ESMO) Handbook of Advanced Cancer Care was translated by some SSCC members into the Turkish language; it has been used by students, physicians, and nurses who deliver palliative care in their clinics.
- Several members of SSCC translated The Council of Europe report (Rec 2003/24) on Organization of Palliative Care (Recommendation 24 of the Committee of member states) into the Turkish language and distributed it to medical centers, the Ministry of Health, and other places related to the organization of palliative care.
- The INCTR Palliative Care Handbook has been translated and distributed to thousands of doctors by the Ministry of Health.

Initiatives to develop healthcare professional leadership in palliative care:

There are no professional leadership or fellowship programs in palliative care.

Officially recognized medical certification:

The NPCP (including accreditation) is almost completed and should be ready for implementation during 2012.

Capacity of palliative care workforce training in Universities and Medical Schools:

- Turkey possesses 80 medical schools: 40 of them have palliative care as a mandatory component and 10 as an optional component (estimate based on personal experience).
- There are 20 full Professors of Palliative Medicine, ten assistant professors and approximately 30 “other professors” (estimate based on personal experience).

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- The availability of essential medications is increasing in the Turkish market.
- Some new forms of opioids have been issued for palliative care (but there is still a lack of some opioids).
- National opioid production for oral immediate release and continuous release tablets has started.

Developments/opportunities/barriers relating to the accessibility of essential medications:

- The accessibility of essential medications is improving slowly (however, there are still some difficulties in prescribing opioids).
- The Ministry of Health is working to delete red prescriptions (using an e-prescription system).

Developments/opportunities/barriers relating to the affordability of essential medications:

Medications may be reimbursed for home-based palliative care.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

There is no information available at this time.

Initiatives to promote attitudinal change in relation to ‘opiophobia’:

There have been several meetings and discussions to educate the community and health workers about opiophobia.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There is no information available at this time.

Initiatives that consider access to essential medication as a legal and human right:

Pain and symptom management has been accepted as a legal and human right in the NPCP.

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- There are regulatory difficulties related to prescription dose limits (and excessive bureaucracy).
- There is insufficient economic support and problems related to reimbursement.
- There is inequality in the distribution of resources.
- There is a lack of regulations relating to palliative care (DNR, advanced directives, etc.).
- However, the Ministry of Health has declared that it is to publish national palliative care legislation soon with an organization model and plans. There is also to be new legislation in relation to the reimbursement of palliative care services.

Much consensus relating to palliative care has been developed; the concept of palliative care has been disseminated slowly throughout Turkey. Several meetings have been held with key stakeholders and policy makers about implementing home-based care and establishing the NPCP

The impact of these policy changes and ways in which they have been important:

It is difficult to improve and expand the NPCP throughout the country without these policy changes being implemented.

Development of a national palliative care consensus:

A great deal of improvement and consensus has been developed since 2008.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

Several national meetings have been held with stakeholders and policy makers about implementing home-based palliative care, and establishing the NPCP.

Development of an advocacy framework for integrating palliative care into the health care system:

Some initiatives, developed by the Ministry of Health, Cancer Control Department, and the members of several organizations including the Turkish Oncology Group, Palliative Care Organization, Medical Oncology Organization, and the Association of Pain, have involved the setting up of a palliative care committee and working in close collaboration with Turkish universities.

Strategies to improve political awareness and government recognition of palliative care:

There have been national meetings, debate and discussion on some TV programs, and some articles published in magazines and newspapers.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

Several small cancer NGOs have developed palliative care funding initiatives.

Involvement with the European Union in relation to hospice and palliative care initiatives:

There is only one project currently working with the European Union in relation to hospice and palliative care initiatives (Access to Opioid Medication in Europe - ATOME).

Development of initiatives framing palliative care as a 'human right':

Palliative care has been accepted as an essential human right in the new NPCP.

General legislation relating to palliative care:

Palliative care legislation relating to the NPCP is in process and should be implemented in 2012.

Published national documents relating to palliative care standards and norms:

Palliative care standards relating to the NPCP are in process and should be implemented in 2012.

National Plan or Strategy of Palliative Care:

The NPCP is in process and should be implemented in 2012.

National Cancer Control Strategy:

The National Cancer Control Program (including palliative care) is available online:

<http://www.tapdk.gov.tr/tutunalkontrol/Ulusal%20Kanser%20Kontrol%20Program%C4%B1,%202009-2015.pdf>

National HIV/AIDS Strategy:

There is no information available at this time.

National Primary Health Care Strategy:

There is a National Primary Health Care Strategy but it does not contain an explicit reference to palliative care provision.

Designated policy maker for the delivery of palliative care services:

The Department of Cancer in the Turkish Ministry of Health is the designated policy maker for the delivery of palliative care services.

Department of Health specific responsibility for the delivery of palliative care services:

As above.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

There is no information available at this time.

Opioid legislation/Pain guidelines:

- All doctors can write a prescription for opioids but they must use prescription forms of different colour (red, green). Opioids are available in both pharmacies and hospitals.
- Pain guidelines are available.

Funding of palliative care services:

- Partial payment may be required for home-based palliative care consultations.
- Full payment may be required for palliative care hospitalisation and medications.

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006**Change in public awareness or perception of hospice and palliative care:**

Public awareness and perception of hospice and palliative care has increased recently.

Major public discussion, debate or controversy about hospice and palliative care:

There has been public discussion, debate and controversy about DNR, euthanasia and terminal sedation.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

Some TV programs and articles in magazines and newspapers have broadened awareness and understanding of hospice and palliative care.

Hospice or palliative care 'success' stories:

Awareness and perception of palliative care amongst healthcare personnel and political groups has increased following meetings organised by the Supportive Care in Cancer Subgroup in the Turkish Oncology Group.

Initiatives seeking the legalisation of euthanasia or assisted dying:

There are no initiatives for the legalisation of euthanasia.

Hacettepe Oncology Institute will commence "Train the Trainer" courses in 2013, which will be followed by local training of healthcare professionals (certified by the Ministry of Health). The availability of essential medications is increasing in the Turkish market

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

Hospice and palliative care is developing in Turkey; almost 500 home care units (providing some form of palliative care) operate in nearly every city in Turkey and the NPCP is almost completed.

Most significant issues facing hospice and palliative care in the next three years:

- Education for the community, healthcare workers and educators in palliative care needs to be improved.
- Improved palliative care legislation.
- Reimbursement of services.

Implications for palliative care relating to the current economic crisis:

The current economic crisis will slow reimbursement of services and the building of new palliative care units.

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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|-----------------------|
| Volunteer hospice team | 2 |
| Hospital palliative care support team | 0 |
| Home palliative care support team | 3 |
| Mixed palliative care support team | 0 |
| Palliative care units in tertiary hospitals | 0 |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 0 |
| Day hospice/day care centre | 0 |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

Personal estimates/estimates provided by experts

Additional comments:

Although there are no specific hospices/palliative care units providing day care for terminally-ill patients in Ukraine, there are a large number of social care day centers/clubs for the elderly which provide psycho-social support for palliative care patients.

Palliative care services for children:

There are not less than 100 paediatric hospital palliative care support teams throughout Ukraine (4,000 beds); there is one paediatric home palliative care support team.

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|------|--|
| 1994 | 'Hospice' is included in the Ministry of Health list of medical establishments in the Ukraine. |
| 1997 | Ministry of Health Declaration No. 356 relating to the registration and delivery of strong opioids is published. |
| 1999 | The Donetsk Regional Oncological Centre opens with a nursing team for patients with advanced disease and a volunteer home care team. It is also the base for the first Ukrainian Palliative Care Teaching Centre, at the Donetsk State Medical University. |
| 2004 | The Association of Minimally Invasive & Palliative Therapy translates and publishes the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organization of palliative care). The report is distributed to hospital superintendents to improve awareness about palliative care and the hospice movement. |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

- (1) The Law of Ukraine "On Amendments to the Basic Laws of Ukraine about public health to improve health care provision" of 7.7.2011, № 3611-VI, a separate special article 35-4, Palliative Care, adopted by the Parliament of Ukraine was the most significant achievement in the development of palliative care in Ukraine since 2006. It guaranteed that: "Palliative care is given to patients at the last stages of incurable disease, which includes a series of measures to alleviate the physical and emotional suffering of patients, as well as providing psychosocial and moral support to their families". Palliative care is provided free of charge by health care institutions where the patient receives secondary (specialized) or tertiary (PHC) medical care.
- (2) An important event that significantly improved the development of palliative care in Ukraine was the creation of the "All-Ukrainian League on Palliative and Hospice Care" in 2011 - a non-governmental organization which extended the existing achievements of NGOs and consolidated the efforts of public and professionals, academics and officials, politicians and public figures in relation to the formation and development of palliative care services. Currently, the League (headed by former Minister of Health of Ukraine V.M.Knyazevych), has branches in most regions of Ukraine, working in accordance with the Memoranda of the Ministry of Health and Department of Human Services of Ukraine, the National Academy of Sciences and the National Academy of Education of Ukraine.
- Since 2008, with the assistance of the Minister of Health of Ukraine V.M.Knyazevych, there has been development and discussion about draft regulations that have significantly enhanced the regulatory framework of palliative care and improved hospice provision, the provisions of the Department of Palliative Care, provisions for mobile teams, palliative care aid procedure, availability and accessibility of opioids, etc; all these developments are soon to be finally approved by the Cabinet of Ministers, Ministry of Health of Ukraine and other public institutions.
- From 2006, on the initiative of the "All-Ukrainian League on Palliative and Hospice Care" and other NGOs and with the support of the International Renaissance Organization, Open Society Institute, and the European Association for Palliative Care, a collaboration of public health specialists in Ukraine prepared a number of action plans to improve palliative care services and hospices in Ukraine. Particular progress has been made in the last two years, mainly thanks to the active role of the "All-Ukrainian League on Palliative and Hospice Care." All these initiatives have intensified the activities of health care institutions in establishing palliative care, and the development of research and training.
- The Coordinating Council for Palliative and Hospice Care in Ukraine (Order № 210 of 17.04.2008) was created in April 2008, from a public initiative developed by the Ministry of Health of Ukraine. Tasks of the Council include: interagency and interdisciplinary coordination of institutions, agencies, and authorities on the further development of palliative and hospice care, ensuring inter-sectoral collaboration in developing the State program of hospice and palliative care in Ukraine until 2014.
- In July 2008, the Institute of Palliative and Hospice Medicine was established by the Ministry of Health of Ukraine (initiative № 159-O of 24.07.2008). The Institute is defined as the basic (main) methodological and clinical institution of the Ministry of Health of Ukraine for palliative and hospice care. The Institute is entrusted with the following tasks: development and control of the State program, improving regulations governing the provision of palliative care, training, development of hospices, the development and enforcement of standards and protocols, and raising public awareness about palliative care.
- On the 26th of June 2009, for the first time in the history of independent Ukraine, the Ministry of Health of Ukraine enforced Order № 463 "Approval of the development of palliative care in Ukraine for 2009-2010" and on the 29th of April 2010, the Board of Health of Ukraine was presented with a separate issue "Development of Hospice and Palliative Medicine" - they adopted the proposal.
- In 2010, the first form of medicines for palliative and hospice care ("State form of medicines", 2010 paragraph 9) was created and in 2011, the second form of medicines for palliative and hospice assistance ("State form of medicines", 2011 paragraph 8.) was approved by the Ministry of Health of Ukraine Order № 159 of 23.03.2011.
- In December 2010, the Department of Palliative and Hospice Medicine was established within the National Medical Academy (d after P.L. Shupyk). Personnel in the department have developed a curriculum of thematic improvement and held postgraduate palliative care training for doctors and nurses of primary and secondary networks and professionals working in specialized cancer institutions, offices and hospices.
- However, there are still problems with accessibility to oral forms of morphine, especially outside the hospital, and this remains unresolved in Ukraine - a situation that causes resentment and even anger not only among patients and their families, but also doctors, the general public, and domestic and international human rights organizations. Therefore, proposals to reduce the basic legal and organizational barriers have been formulated in order to improve access to opioid analgesics for palliative care patients. A working group of experts has been formed comprising of representatives from the Institute of Palliative and Hospice Medicine, Ministry of Health of Ukraine, Institute of Pharmacology and Toxicology of Ukraine and practitioners working in the field of palliative care, to develop clinical guidelines, standards and protocols on chronic pain in cancer patients (Ministry of Health of Ukraine of 27.09.2010 p. № 810). The working group has developed clinical guidelines "Control of pain in oncology".
- Since 2006, the number of hospice and palliative care units has continued to grow. Today, a variety of palliative care facilities are available: organizational structures including those provided by established church and community charities, (Red Cross, etc.) are open in many cities of Ukraine. Palliative Care Departments and individual hospices operate in Kyiv, Kharkiv, Ivano-Frankivsk, Lviv, Lugansk, Luts, Donetsk, Mykolaiv, Kherson, Sevastopol, Odessa, Chernihiv, Dubno, etc. Unfortunately, both the size and material/technical base of most existing hospice and palliative care units do not meet international standards and the conditions for patients staying in many of these institutions are not always satisfactory.

- In some regions, institutions of social protection have home care services with elements of palliative care provided by multidisciplinary teams of specialists, including doctors, nurses, psychologists and social workers. For example, in 2009, local programs of palliative care at home for patients with cancer were developed and realized by the Institute of Palliative and Hospice Medicine of Health Ministry of Ukraine in Kiev and in the Pechersk district of Kyiv (in conjunction with the Pechersk District of Kyiv State Administration). This type of palliative care is mainly implemented in regional centers in the major cities of Ukraine (most people who are in need of palliative care at home still cannot receive it, especially the inhabitants of small towns and villages).
- Currently, the hospice departments of health care settings have extremely limited resources and are often unable to provide patients with palliative care due to lack of medical equipment, effective anaesthetics, special mattresses to protect against bedsores, etc.
- The most acute demographic problem is an extremely high mortality rate. According to the State Statistics Committee of Ukraine (2006–2011), the annual mortality rate in Ukraine is approximately 700,000 people per year. Only 5% of people die in hospitals, where they receive the required specialized medical care and adequate pain relief – approximately 85% of patients die at home.
- According to the order of the Ministry of Health of Ukraine from 15.07.2011 № 420 “On approval of the guidelines for calculating the needs of the population in health care” (paragraph 3), the calculation of the need for palliative care is undertaken taking into account the factor of need for palliative care (0.80 from the number of patients who died last year). Thus, annually about 600,000 people require hospice and palliative care, and more than 60,000 of these are patients with cancer. In addition to this, family members of palliative care patients also require professional palliative care. Many Ukrainian citizens die at home, suffering from physical and psychological pain. The number of palliative care patients and relatives who care for them is estimated at approximately two million people each year.
- In Ukraine, the first hospices were established in the late 1990’s and early 2000’s, in Lviv, Ivano-Frankivsk, Korosten, Kharkiv, Lutsk and other cities.
- (3) The International Renaissance Foundation has organised several training courses for medical personnel in Ukraine. Ivano-Frankivsk Hospice formed a training centre, and the Medical University began post-graduate training of family doctors.

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: (2) Since 2006, palliative care units have appeared in many cities of Ukraine, particularly in hospitals in Kharkov, Lviv, Lugansk, Lutsk, Donetsk, Sevastopol, Kiev, Chernigiv, Dubno, etc. However, the development of palliative medicine is very slow. There are separate departments of palliative medicine at 20 hospitals operated by the Ministry of Health of Ukraine.
- Nursing homes: (2) There are no specific palliative care departments in nursing homes. Providing palliative care in these institutions does not have separate regulation (protocols, guidelines).
- Residential homes for the elderly: (2) There are no separate palliative care units in residential homes for the elderly or nursing homes belonging to the Department of Human Services of Ukraine. Treatment of palliative care patients in these institutions has not yet met the required standard and is therefore (in general terms) within a doctor’s remit.
- Other community settings: (2) Palliative care in clinics is mainly provided by GPs, oncologists, therapists, and other geriatric physicians. Family members take care of palliative care patients at home. There are no services to provide palliative care at home from health care facilities belonging to the Ministry of Health of Ukraine.

Expansion from a focus on cancer patients to address the needs of ‘non-cancer’ patients:

- (1) Newly established hospices provide palliative care for non-cancer patients, as well as cancer patients.
- (2) Since 2006, the number of non-cancer patients receiving palliative care in hospice and palliative medicine departments in Ukraine has increased. The most frequent causes of death (2008–2011) were diseases of the circulatory system (70%), neoplasm (13%), external causes of death (7%), diseases of the digestive system (4%), and respiratory disease (3%). Ukraine is one of the demographically oldest countries in the region, so palliative care is of primary importance. In 1997, the proportion of people aged 60 years and over accounted for 18.4% of the total population; in 2010 it was 20.8%, and by 2026 this figure is expected to increase to 24.7%. The percentage of people aged over 70 years increased from 7.7% in 1990 to 11.4% in 2010 and the number of people older than 75 years in 2011 is estimated at approximately three million. Currently, in Ukraine more than 910,000 patients with malignant neoplasms are registered in cancer care settings; each year, 160,000 new cases of the disease are registered, and 80,000 patients die from cancer annually. Each year, more than 5,000 HIV/AIDS patients die in Ukraine. Ministry of Health of Ukraine Directive from 03.07.2007 № 368 “On approval of clinical protocols to provide palliative care, and immunosuppressive therapy of symptomatic patients from AIDS” has improved palliative care treatment for HIV/AIDS patients. Directive of the Ministry of Health of Ukraine from 27.12. 2007 № 866 “Confirmation of some provisions of hospice and palliative care department for patients with HIV and AIDS” provides basic definitions of palliative care, and in delivering the main tasks and activities relating to palliative care for HIV/AIDS patients. In the Department of Palliative Medicine, palliative care beds for HIV/AIDS patients are within the control centre for HIV/AIDS in Poltava, Odessa, and Vinnitsa. Legislation relating to palliative care for TB patients includes: 11.06.2010, the Ministry of Health of Ukraine Directive № 483 “Approval of some of the hospital/Hospice (palliative care units, palliative care beds) for patients with tuberculosis.” Palliative care for TB patients is available in Sevastopol, Kherson and Mykolaiv TB dispensaries. There is a precedent for opening a palliative care unit in Cherkasy and Chernihiv regional psychoneurological hospital for patients with a mental illness.

Perceived barriers to the development of hospice and palliative care:

- (1) Lack of financing (including from international sources)
- Lack of palliative care education
- Lack of united efforts amongst NGOs
- (2) Lack of necessary medical regulation and clinical protocols
- Lack of regulatory framework for the functioning of the institutions (hospices, units, health teams)
- Problems with the use of opioids
- Lack of coordinated actions between health and social services institutions (nursing homes, etc.)
- Lack of qualified personnel (including volunteers)
- (3) Misunderstanding about the importance of palliative care at the administrative level
- Slow development of healthcare reforms
- Restrictive legislation relating to the use of opioids.
- Absence of oral morphine
- Inadequate financing of healthcare in general (and palliative care in particular).
- Inadequate knowledge about hospice and palliative care amongst medical personnel.

Perceived opportunities for the development of hospice and palliative care:

- (1) Cooperation with governmental structures
- Relatively good material and educational base inherited from Former Soviet Union
- Improved political will
- (2) The adoption of a comprehensive national program indicating expenditures, concrete measures, deadlines, etc.
- Development and approval of all regulations
- Decision on the funding of services (budget funding)
- The active role of the "All-Ukrainian League on Palliative and Hospice Care" consolidated the efforts of public, government agencies and officials, experts and scholars for the First National Congress on palliative care (26-27 September 2012); also the participation of experts from the "All-Ukrainian League on Palliative and Hospice care" for developing the State program of palliative care by 2020. Ukraine will have the possibility of developing a palliative care system over the next 5-7 years.
- Ensure the establishment and funding of the National Clinical Research Center for Palliative Care, as the main institution for palliative care in Ukraine, to develop and approve procedures for the operation of palliative care in Ukraine.
- Enhancing international cooperation of the League to apply best practices and approaches for palliative care in Ukraine.
- (3) Legalisation by an Order of the Minister of Health Care of Ukraine for provision of palliative care.
- Legislation provided by the Cabinet of Ministers of Ukraine for the use of opioids in the healthcare system
- Introduction of educational palliative care programs for the students of all medical institutions and colleges.
- Registration of oral morphine.

Other issues relevant to the development of hospice and palliative care:

- (2) Involvement and participation of NGOs in the development of palliative care since 2006 has intensified activities of the Ministry of Health of Ukraine and Department of Human Services, regional authorities and research institutions and facilitated the accelerated development of palliative care.
- The most urgent issues are those of effective pain control and other clinical symptoms that cause the greatest suffering for patients with chronic incurable diseases, including those in the terminal period of cancer; accessing medical care is a fundamental human right.
- The prescribing of opioid analgesics for control of chronic pain in palliative care patients (especially outpatients) is extremely problematic.
- The "All-Ukrainian League on Palliative and Hospice Care" and other NGOs, experts and managers of health care (with the support of international foundations and organizations) play an active role in the following areas:
 1. Improving the legal framework regarding the use of opioid analgesics for control of chronic pain in palliative care patients.
 2. Control of chronic pain syndrome for palliative care patients, according to existing clinical standards and protocols of WHO.
 3. The formation of public opinion regarding the use of opioid analgesics for control of chronic pain for palliative care patients.
 4. Promoting the registration and use of oral morphine and transdermal systems.
- After the first direction of the MOH of Ukraine, working groups were established that were involved in the development of relevant changes to the current legal framework regarding the use of opioid analgesics for chronic pain control (MOH of Ukraine № 531 from 02.07.2010r. "On a Working Group on improving regulations to increase the availability of palliative patients with chronic pain syndrome in the terminal stage of life to modern highly efficient analgesic drugs, including opioid analgesics")
- In 2010, the Department of Palliative and Hospice Medicine was established at the National Medical Academy, and personnel developed a curriculum of thematic improvement for doctors and nurses of primary and secondary networks, and professionals working in specialized cancer institutions, departments of palliative care and hospice. These programs included theoretical and practical issues in the control of chronic pain, according to current clinical standards and WHO protocols.
- International experience demonstrates the urgent need to implement modern medical technologies for pain control, and provide professionally trained medical specialists to provide palliative and hospice care.

- The "All-Ukrainian League on Palliative and Hospice Care" conducts round tables and press conferences on opioid issues, attracting mass media interest.
- Oral morphine dosage forms (e.g. morphine sulphate, hydromorphone, and oxycodone) are not yet registered in Ukraine. Only morphine hydrochloride is registered (injection of 1% in 1ml ampoules). In accordance with the Order of the Ministry of Health of Ukraine in 2011, 04.11.2011, № 759, "A working group on improving the regulations of chronic pain syndrome for palliative care patients should be established"; a working group, headed by First Deputy Minister of Health R.O. Moyiseyenko has begun to attempt to solve the problem of oral morphine production in Ukraine.

Vitality

THE VITALITY OF PALLIATIVE CARE**National Associations of Palliative Care:**

- The Association of Palliative and Hospice Care (Асоціація паліативної та хоспісної допомоги) was formed in 2010; the association has a web-site (www.palliativ.kiev.ua) and is representative of the whole country.
- The All-Ukrainian Association of Palliative Care (Всеукраїнська Асоціація паліативної та хоспісної допомоги) was formed in 2007 and is representative of the whole country.

Directory or catalogue of palliative care services:

There is a directory or catalogue of palliative care services in process: the list of hospice care settings is available on the Internet - the problem is that there is no definition of "hospice", so many institutions that refer to themselves as "hospice" are actually "nominal" hospices and therefore should not be included on the list.

Congresses, scientific meetings or scientific journals in palliative care:

There is a "Social Policy towards the Incurably Ill" scientific conference held in Kyiv and attended by approximately 80 participants (authorities in health care and social policy, economists, practitioners etc.

Palliative care research capacity:

- Research centres include: Institute of Palliative and Hospice Medicine
- Researchers include: Iurii Gubsky, prof., MD (jurganik@ipnet.kiev.ua); Anatoly Tsarenko, PhD, MD (atsarenko@gmail.com); Alexander Wolf, Master of Social Work (info@palliativ.kiev.ua); Olga Tolstych, Vira Tchajkivska, Leonid Stadnik, Inna Kuzhel.

Palliative care collaboration:

- There is collaboration between the Association of Palliative and Hospice Care and British, Polish, Slovakian, Hungarian, Slovenian, Spanish, Swedish, Belgian, and Georgian National Associations of Palliative Care (and many others). Most collaboration involves issues of capacity-building.
- Pioneers include: the Association of Palliative and Hospice Care, All-Ukrainian Association of Palliative Care, Institute of Palliative and Hospice Medicine, and the Council for Patient Rights and Safety.
- The development of hospice care in Ukraine commenced in 2006, and its pioneers are the representatives of the organizations mentioned above (who currently have approximately the same impact on the development of the movement at the national level - the financial crisis is the greatest barrier to further development).
- Each year, the Association of Palliative and Hospice Care and other organizations arrange events (conferences, press releases, presentations, etc.) on World Hospice and Palliative Care Day to raise awareness and attract attention to the problems of providing palliative care. Special attention is paid to the charity concerts (Voices for Hospices program) which has the "Artists support hospices" in Ukraine. Each concert organized by the Association attracts on average 100 guests (the maximum number of guests is 350 and the minimum number is 30).

Worldwide palliative care alliance level of development:

3A (Isolated palliative care provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- (1) In 2009, the Department of post-graduate education (National medical academy of post-graduate education) organised a series of two-week palliative care education and training course for approximately 300-400 medical workers and organisers of medical care. Since 2009, the Department of Palliative and Hospice Medicine (National medical academy of postgraduate education) have provided the following courses for physicians: "Organisation and provision of palliative care in primary and secondary levels" (39 hours); "Organisation and provision of palliative and hospice care in specialised (tertiary) health care settings" (39 hours and 78 hours); "Basics of palliative and hospice care in oncology" (78 hours); "Organisation and legal issues of palliative and hospice care in primary and secondary levels" (39 hours). The following courses have been provided for nurses: "Basics of nursing care in palliative and hospice medicine" (39 hours) "Nursing care in palliative cancer care" (78 hours). In conjunction with the Department of Internal Diseases and Geriatrics, the Department of Palliative and Hospice Medicine (National medical academy of postgraduate education) have provided the course: "Basics of education on palliative care" for trainers (156 hours). These courses are provided either in Kyiv (in the Academy) or outside the Academy in facilities which provide offer a suitable location accommodation, transport etc. All the courses are certified by the Academy and regarded as an invaluable tool for educating physicians and nurses about palliative care.
- The Association of Palliative and Hospice Care organised five palliative care training courses for approximately 100 medical workers and organisers of medical care from different regions of Ukraine. In April 2012 (in Kyiv), the association organised a training course: "Rehabilitation, psychological and social support for parents with children who have cerebral palsy". This was achieved with the financial support of the Australian Government. The association have delivered presentations on a variety of topics: for example, equipment for the rehabilitation of children at home (especially the emotional development of children and teenagers); skills of effective communication with children who have a disability; and psycho-emotional support for parents of children with disabilities. Printed materials offering practical advice for the care of children with disabilities has been provided (addresses of organizations that provide rehabilitation services, including dolphin therapy, painting therapy, therapy with horses, etc.) Following the training sessions, all participants received free diapers, new clothes, and other gifts (for both parents and children); a doctor of physical therapy provided a course of free massages. Financial support for gifts was provided by a number of donations from anonymous benefactors; other donations were received in collection boxes which are placed in many different shops in Kyiv.
- (2) Training and development of those involved in providing of palliative care has intensified in recent years, thanks to the cooperation of the All-Ukrainian League on Palliative and Hospice Care, other NGOs, academics and the Ministry of Health. Since 2009, a palliative care course has been included in the training program for doctors and nurses. There is a great need to provide additional training for those that provide palliative care. Ukrainian experts, doctors, social workers, Geriatriests, employees of public charities, etc. do not possess the full range of necessary knowledge and skills to provide effective, high-quality palliative care. Lack of suitably trained staff is one of the reasons why palliative care is often unavailable for many patients; especially in relation to pain relief (another barrier is the lack of money). It is therefore vital that palliative care training programs and research activities are introduced into undergraduate and postgraduate University curricula (this is the key to changing existing situations and developing new approaches for providing palliative care).
- A new era in the postgraduate training of palliative care personnel began in January 2010 at the National Medical Academy of Postgraduate Education, Department of Palliative and Hospice Medicine, when training for doctors PCBs, oncologists, surgeons, anaesthesiologists, local general practitioners, family doctors, and Geriatriests was provided.

- An important future task is to establish collaboration between the Institute for Palliative and Hospice Medicine, experts of other specialized research institutes, the Ministry of Health of Ukraine and NAMS departments of medical schools. This collaboration will enable research to be conducted that can create a scientific evidence-base in palliative and hospice medicine; this will also ensure that highly qualified staff will be produced in this area. This important issue was discussed at the First National Congress of Palliative Care in September 2012. Also in 2012, the All-Ukrainian League of Palliative and Hospice Care signed a memorandum of cooperation with the National Academy of Sciences of Ukraine and the National Academy of Medicine.

Specific developments in under-graduate palliative care education initiatives:

- Medicine: (3) A program of palliative care training for undergraduates has commenced in two colleges in the towns of Cherkassy and Dubno. At present, undergraduate palliative care education programs are developed on the basis of EPEC and ELNEC criteria and are being prepared for adoption at the Ivano-Frankivsk and Donetsk Medical Universities.
- Nursing: (2) This course will be an elective one for future doctors and nurses according to programs approved by the Ministry of Health of Ukraine.
- Social work: There is no information available at this time.
- Other professions: There is no information available at this time.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: (1) Special training programs for doctors have been developed and introduced by the Department of post-graduate education (National medical academy of post-graduate education). The programs include education for organisers of health care as well as for practicing physicians.
- (3) Post-graduate training is provided for hospice personnel and for doctors of other specialties such as oncology, family medicine, pulmonology, and psychology (and others) by the Institute of Palliative and Hospice Medicine in Kiev; training is undertaken at the Department of Palliative and Hospice Medicine in Kyiv Medical Academy, Ivano-Frankivsk Medical University, and the training centre at Ivano-Frankivsk Hospice.
- Nursing: (1) Special training programs for nurses have been developed and introduced by the Department of post-graduate education (National medical academy of post-graduate education). The programs include education for organisers of health care as well as for nurses.
- (2) The training of nursing staff requires special attention. One of the first steps in this activity should be the training and thematic development of nurses who provide care for patients in geriatric, therapeutic, and neurological wards, departments of nursing care, hospices, and district services; also nursing staff at the Red Cross, religious institutions and other health and social institutions which provide forms of palliative care for patients. This postgraduate training has been provided since 2010 by the National Medical Academy of Postgraduate Education, Ivano-Frankivsk Medical University, and Uzhgorod National University. Employees of the Department of Palliative and Hospice Medicine, National Medical Academy of postgraduate education, developed six thematic education programs for nurses in palliative and hospice care (39, 78 and 156 hours), based on best European practice and other contemporary clinical and scientific-pedagogical experience in the field of palliative medicine.
- In 2010, the department of palliative and hospice medicine of therapy and geriatrics, Medicine, National Medical Academy of postgraduate education, developed curricula of thematic improvement for teachers of medical and social workers (156 hours) and for doctors and nurses in hospice, palliative care units, nursing units and long-stay institutions, medical and social services, homes for the elderly and disabled, and educational institutions that prepare health and social workers.
- School curricula "Palliative Care" has been developed by the head of the Department of Palliative and Hospice Medicine, National Medical Academy of post-graduate education, Professor Yu. Hubsikiy together with assistant professor A.V. Tsarenko and the rector of Zhytomyr Institute of Nursing Professor V. Shatylo. The curricula presents a modern view of palliative care, and general medical aspects of palliative nursing (especially nursing care for pain control and other symptoms in terminally-ill patients). The school curricula are recommended for the preparation of students in higher education and third level accreditation institutions in the course of palliative medicine and nursing.

(3) Other postgraduate palliative care initiatives for nurses have been developed at Dubno, Cherkassy, and Ivano-Frankivsk colleges

- Social work: (1) Special training programs for social workers have been developed and introduced by the Department of postgraduate education (National medical academy of post-graduate education). The programs include education for organisers of health care as well as for social workers.
- (2) Issues concerning palliative and hospice care for geriatric patients are included in the curricula of therapy and geriatrics, and Medicine, National Medical Academy of post-graduate education. Members of the Department of Palliative and Hospice Medicine, National Medical Academy of post-graduate education, are working on the development of training programs in palliative and hospice care for social workers and medical staff of the Department of Human Services.
- (3) The training centre of the Ivano-Frankivsk Hospice conducts training in palliative and hospice care for social workers in the Ivano-Frankivsk region.
- Other professions: (1) The Association of Palliative and Hospice Care has organised two training courses for volunteers engaged in hospice care. On both occasions, approximately ten volunteers attended, and approximately ten practicing medical workers, psychologists, representatives from social protection services, church and other charitable organizations also attended.

Translation of palliative care documents or other materials:

- (1) Guidelines on pain management are based on the translation from UK Standards of pain management (this was a necessary precondition of the Ministry of Health); the Association of Palliative and Hospice Care has translated some journal articles and other documents.
- (2) Funding for the translation of palliative care documents has been provided by the International Renaissance Foundation.
- (3) EPEC/tm-O and ELNEC Trainer's Guides, several documents about human rights for palliative care patients (Human Rights Watch), WHO recommendations on pain and other palliative care materials have been translated.

Initiatives to develop healthcare professional leadership in palliative care:

(3) Initiatives to develop healthcare professional leadership in palliative care have been undertaken by the International Renaissance Foundation and Open Society Institute.

Officially recognized medical certification:

(1) Work on officially recognized medical certification has commenced within the Ministry of Health Institute of Palliative Medicine.

Capacity of palliative care workforce training in Universities and Medical Schools:

Ukraine has an estimated 60 palliative care courses (including those courses providing education for future nurses and physicians).

Developments/opportunities/barriers relating to the accessibility of essential medications:

(1) It is difficult to access essential medications due to educational, logistical, and other barriers.

Developments/opportunities/barriers relating to the affordability of essential medications:

(2) The price control of opioids was very restrictive until 2008.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

- (1) A number of proposals from the Institute of Palliative and Hospice Care relating to cancelling some legal limitations relating to opioids have been given to the Ministry of Health. They are about cancelling different legal limitations.
- (2) The 02.07.2010 Directive of the Ministry of Health of Ukraine № 531 "Creation of working group on improving legislation to increase the availability of palliative patients with chronic pain syndrome in the last stage of life to modern highly efficient analgesic drugs, including opioid analgesics," and 04.11.2011 - Directive of MOH of Ukraine № 759 "Creation of working group on legislation of chronic pain relief".
- The first part of a process to improve accessibility to opioids for pain relief has commenced. As soon as these amendments are approved, a number of regulatory barriers will be eased and the suffering of hundreds of thousands of Ukrainian people will be alleviated. The Ministry of Home Affairs, Department of Human Services, State Service of Youth and Sports of Ukraine, and Ministry of Education will all be involved in this process.

Initiatives to promote attitudinal change in relation to 'opiophobia':

- (1) The Institute of Palliative and Hospice Care together with Department of post-graduate education (National medical academy of post-graduate education) organises courses for different groups of medical workers on this issue; the Association of Palliative and Hospice Care, during its advocacy events (charity concerts) also discuss this issue.
- The Institute of Palliative and Hospice Care together with Department of post-graduate education (National medical academy of post-graduate education) have published a book "Pharmacotherapy in palliative and hospice care" and disseminated it among different healthcare providers.
- (2) Problems connected with the availability of opioid analgesics in the required quantity for palliative care patients affirm existing disparities in their use and prescribing - according to both national law and international standards. It is of paramount importance for the development of palliative care that the legal framework and basic directions of State policy in this area are identified and amended.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

(3) Initiatives that examine access to opioid medication for economically disadvantaged persons have been funded by the International Renaissance Foundation.

Initiatives that consider access to essential medication as a legal and human right:

There have been initiatives that consider access to essential medication as a legal and human right

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

- (1) The Institute of Palliative and Hospice Care together with the Association of Palliative and Hospice Care have developed guidelines, "formulars" and other necessary documents on pain management, but the system of disseminating opioids is too strictly regulated by other stakeholders in the process (who would prefer to maintain the current situation).
- (2) There is a constantly expanding list of opioids, but their price is regulated by the State (among these are opioids used in palliative care).
- (3) There have been some opportunities relating to the availability of essential medications, but unfortunately their realization depends on the decisions of high-ranking administrative officials.

The Law of Ukraine "On Amendments to the Basic Laws of Ukraine about public health to improve health care provision" adopted by the Parliament of Ukraine is one of the most significant achievements in the development of palliative care

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- (1) The legal definition of palliative care in the law of health care (2011).
- (2) The introduction and development of palliative care systems/services in Ukraine is impossible without an appropriate legal framework in medical and social care governance, including adequate pain relief, accessibility to hospice and palliative care services, mobile teams, development s, and the development of private palliative care institutions. Therefore, the MOH of Ukraine, through the initiative and efforts of the general public and international support, pays great attention to the legal issues relating to service provision of palliative and hospice care in recent years.
- According to legislation, one the main priorities of the Ministry of Health of Ukraine is to implement government policy aimed at preserving the life and health of every citizen, and ensuring the constitutional right to medical care, including social care, and psychological and spiritual support at the end-of-life. This requires the combined effort of both individual institutions and clinical specialists (including oncologists, geriatrists, specialists in family medicine, TB doctors, infectious diseases specialists), social services, hospice and palliative care providers (including hospices, some palliative and hospice beds in cancer therapy and general hospitals, nurses providing palliative care at home), and professional organizations. The development of palliative care has intensified since 2008 when Dr. Knyazevych was appointed as the Minister of Health.
- The 04.17.2008 Directive № 210 on the establishment of the Coordination Council of Palliative and Hospice Care at the Ministry of Health of Ukraine was issued by MOH of Ukraine.
- The July 24, 2008 Directive № 159-0 "Establishment of the Institute of Palliative and Hospice Medicine in Ukraine" as a basic scientific, methodological and treatment facility for palliative and hospice care.
- The 26.06.2009 Directive № 463 "Approval of the development of palliative care in Ukraine for 2009-2010".
- On 19.02.2009, the Verkhovna Rada of Ukraine (Parliament) adopted the Law "Approval of the National Programme on HIV prevention, treatment and support for HIV and AIDS patients for 2009-2013". The list of the main objectives of the programme also includes providing care and support for HIV/AIDS patients (including the organization of palliative care).
- On 23.12.2009, the Verkhovna Rada of Ukraine adopted the Law "Approval of the national program against cancer until 2016", which assumed the task of improving the provision of palliative care for cancer patients, and the expansion of hospice and palliative care.
- In 2010, a joint order of the MOH of Ukraine and the Academy of Medicine of Ukraine was issued: № 409/36 "Tasks and activities of the National Programme against cancer to 2016", in which measures for the development of palliative care for cancer patients are expected (however, it is unknown whether this initiative has been funded).
- In 2010, the first list of medicines for palliative and hospice care was developed ("State form of medicines". Year 2010 Appendix 9); in 2011, the second list of medicines for palliative and hospice care was developed ("The state form of medicines". Year 2011 Appendix 8) - this was approved by the Order of MOH of Ukraine № 159 of 23.03.2011.
- The 17.02.2010 Directive № 208 "Some of the improvement of health", approved the basic conceptual directions of health care reform, including the creation of institutions to provide palliative care (hospices).
- The 02.07.2010 Directive MOH Ukraine № 531 "About creation of working group on improving legislation to increase the availability of palliative care for patients with chronic pain syndrome in the terminal stage of life and accessibility to modern highly efficient drugs, including opioid analgesics."
- The 11.04.2011 Directive of MOH of Ukraine № 759 "About creation of working group on improving the regulations on pain of palliative care patients with chronic pain syndrome."
- (1) The Law of Ukraine "Amendments to the Basic Laws of Ukraine about public health to improve medical care" from 07.07.2011, № 3611-VI, included a separate special article 35-4, "Palliative Care".
- (2) Palliative care is provided free of charge in secondary (specialized) or tertiary (PHC) medical care institutions.
- Methods of palliative care and a list of medical indications for its provision are determined by the executive in the health sector. There is a favourable situation in Ukraine: government agencies, including Ministry of Health of Ukraine, Institute of Palliative and Hospice Medicine and the civil sector, the All-Ukrainian League on Palliative and Hospice Care supported by International Renaissance Foundation, Open Society Institute and other international organizations and foundations have been able to establish effective cooperation for the best possible protection of the rights of palliative care patients and their families (who now form a considerable part of Ukrainian society).
- (3) In 2007, the Law of Ukraine 648-V adopted the State Programme of prevention of tuberculosis, which envisages the provision of palliative care in this area. The Ministry of Health Care of Ukraine (MHC) adopted the Clinical Protocol of providing palliative care to HIV/AIDS patients and following the Act of palliative care in hospices (2008), the MHC of Ukraine formed the Coordinative Council of Palliative and Hospice Care. In 2009, the MHC of Ukraine adopted the Act of measures of development of palliative care in Ukraine and the State Programme of Prevention of Oncological Diseases. This Programme envisages the creation of regional hospices and development of standards for providing palliative care. In 2010, the MHC of Ukraine accepted the order to create a working team whose objective was to develop legislative acts relating to the treatment of pain for palliative care patients and accessibility to opioids. In 2011, the MHC of Ukraine adopted the methodical recommendations for calculating population needs in relation to palliative care; the MHC of Ukraine also signed the Law of Ukraine "Amendment to the Fundamental Law of the Health Care of Ukraine" which includes a chapter devoted to the development of palliative care in Ukraine. Currently this law is enacted in only four pilot regions (Dnipropetrovsk, Donetsk, Vinnytsa, and Kiev). For the remaining regions of Ukraine it will be enacted in 2014. In 2012, clinical protocols for alleviating pain were adopted by the MHC.

The impact of these policy changes and ways in which they have been important:

- (1) It is too early to assess the impact of these policy changes
- (3) It is a very important process (but also a very long one).

Development of a national palliative care consensus:

- (1) There are no standards on providing palliative care, but there are some national guidelines on pain management, developed by the Institute of Palliative and Hospice Care and the Association of Palliative and Hospice Care. In March 2012, the scientific conference "Social policy towards incurably ill" was held and representatives of Help the Hospices assisted in the development of a national palliative care consensus.
- (2) A national palliative care consensus is not yet developed in Ukraine but the All-Ukrainian League on Palliative and Hospice Care is working on this issue.
- The consolidated efforts of the civil sector, healthcare professionals and legal authorities are the main condition for the development of palliative care in Ukraine. This collaboration helps to promote the development of modern legal regulation of palliative care according to international approaches and best practices to achieve optimum availability of palliative care in different regions of Ukraine, at different levels of care of terminally-ill patients (with different types of diseases) and improve the outlook of their lives and the lives of their families.
- Since 2006, the Cabinet of Ministers adopted a resolution regarding certain aspects of palliative care, which has contributed to the development of the discipline in Ukraine.
- International experience clearly demonstrates that it is the cooperation of the State and the general public, sources of funding from the State budget and also charities and the private sector that achieves good results in the development and availability of palliative care. The conceptual principles of palliative care formation in Ukraine should be as follows:
 1. Palliative care must become a necessary and integral part of health and social protection systems.
 2. Financing for institutions and agencies that provide social and medical care (including palliative care) has to be adequate and equal regardless of their affiliation or ownership.
 3. All higher education institutions should include palliative care training programs in their curricula, not only for medical and nursing students, but also for social workers, psychologists, and lawyers.

4. The involvement of private organizations, other NGOs, other associations, and volunteers to implement programs of social and health care, is a necessary condition for the accessibility, efficiency and effectiveness of palliative care. Authorities should support the activities of such organizations if they focus their efforts on providing medical and social, psychological, and legal assistance, as well as moral and spiritual support to patients and their families.
- (3) Clinical protocols relating to palliative care have been introduced into the practice of all medical institutions.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

(2) There were meetings with stakeholders and policy makers to develop palliative care strategies: the week before World Hospice and Palliative Care Day in October 2011; while creating the draft program of medical care (2010-2012); and during the first National Congress on Palliative Care.

Development of an advocacy framework for integrating palliative care into the health care system:

- (2) There is a trend towards the integration of palliative care into the health care and social security system in Ukraine
- In October 2011, a Memorandum of Cooperation was signed between the All-Ukrainian League on Palliative and Hospice Care and the Ministry of Health of Ukraine. Draft legislation has been prepared ready for implementation.

Strategies to improve political awareness and government recognition of palliative care:

- (1) Education; researchers; personal meetings with heads of Ministry of Health, Ministry of Social Policy and Ministry of Economics.
- (2) The strategy to consolidate the efforts of the general public and healthcare professionals (2006-2012), government agencies, including Ministry of Health of Ukraine and Department of Human Services, National Academy of Medical Sciences, National Academy of Education, Institute of Palliative and Hospice Care, and the civic sector: the All-Ukrainian League on Palliative and Hospice Care and its partners, supported by the International Renaissance Foundation, Open Society Institute and other international organizations and foundations.
- Palliative care should be available to the patient in accordance with approved standards and clinical protocols, to meet the needs of the patient at home, in the clinic (as required) and in all other forms of medical institution (including daycare or in specialized hospitals, hospice or palliative care units).
- Public awareness about the problems of providing palliative care needs to be increased through activities that promote the formation of respect for human rights and law, in order to attract the attention of people who make the important decisions.
- In 2011, the All-Ukrainian League on Palliative and Hospice Care appealed to the Government and its agencies (ministries, departments) to explain all the necessary measures in this area; officials from central and regional authorities were invited to participate in the activities of the League, including making regular appearances in print media and on television concerning the value of palliative care, and participating in drafting palliative care regulations (together with representatives of other authorities).
- (3) Strategies include dissemination of information through the mass media, organization of palliative care experts in the MHC, and meetings with deputy ministers and other high-ranking officials.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

- (1) Palliative care development is funded by the International Renaissance Foundation (a branch of Soros OSI in Ukraine).
- (2) In 2009, specialists of the Institute of Palliative and Hospice Medicine, Ministry of Health of Ukraine and representatives of other non-governmental organizations drafted the Concept of the National Programme of Palliative and Hospice Care in Ukraine until 2016, which was approved by the Ministry of Health and submitted to the Cabinet of Ministers of Ukraine. Unfortunately, this project was rejected because of the current financial crisis.
- In 2012, the All-Ukrainian League on Palliative and Hospice Care expert committee developed and submitted for review and approval of the Ministry of Health of Ukraine draft State Programme "Health 2020: Ukrainian dimension. Direction 6.7. Palliative Care".

Involvement with the European Union in relation to hospice and palliative care initiatives:

(2) There has been collaboration with non-governmental organisations for trips to gain palliative care experience in Poland, Slovakia, Germany, Hungary, Romania, and France (and delegates and individual experts from these countries have visited Ukraine). Laws and regulations of the EU have been examined.

Development of initiatives framing palliative care as a 'human right':

- (2) The problem of advocacy, protection and guaranteeing the rights for palliative care patients and their families grows each year, due to the rapid aging of the population of Ukraine and the increasing number of people who die in old age from serious chronic diseases that are accompanied by physical suffering, and emotional and mental disorders; these social problems require interdisciplinary and interagency coordination.
- The right of palliative care patients to available skilled quality health care (as for every citizen of Ukraine), is guaranteed by the Constitution of Ukraine and regulated by the Law of Ukraine "On legislation of Ukraine on Healthcare", and other laws of Ukraine (and some Resolutions of the Cabinet of Ministers of Ukraine and the MOH).
- The Constitution of Ukraine guarantees every citizen the right to medical care in case of poor health, the right for a decent life, right for information and other rights (paragraph 3, 27, 28, 49).
- Analysis of the current situation in Ukraine (made by experts of the All-Ukrainian League on Palliative and Hospice Care), suggests that despite established domestic legislation guarantees, most palliative care patients are faced with a number of violations of their rights. Because of the lack of a basic palliative care system, authorities cannot provide proper palliative and hospice care for people in need, according to international standards and approaches, and therefore cannot fully ensure the rights of palliative care patients.
- One of the most urgent issues for palliative care patients is a violation of their right to obtain, if necessary, adequate and effective pain relief. One of the main reasons for this is the "prohibitive approach" used in regulatory documents of the Ministry of Home Affairs, which regulate the circulation of opioid analgesics. Providing timely and adequate pain relief (especially provision at home) is difficult because of complicated procedures of prescribing and dispensing opioid analgesics within national drug policy: the Law of Ukraine "On measures against illicit trafficking of narcotic drugs, psychotropic substances and precursors and their misuse," combats the illicit trafficking of opioids and psychotropic substances.

An important event that significantly improved the development of palliative care in Ukraine was the creation of the non-governmental organization "All-Ukrainian League on Palliative and Hospice Care" which extended the existing achievements of NGOs

- Issues related to the development of palliative care require the review of legal regulations and adequate funding for palliative care, the achievement of equal access to palliative and hospice care in different regions of Ukraine (at different levels of care for terminally ill patients with different types of diseases). One of the main conditions for the realization of these objectives is to consolidate the efforts of the civil sector and the state.
- At the end of 2011 (for a population of 45 million people in Ukraine), inpatient palliative care was provided in only 23 institutions of hospice and palliative care: hospice and palliative care departments at cancer centers, clinics, multi-disciplinary hospitals, comprise of approximately 800 palliative care beds. This includes hospices and non-governmental charitable religious organizations. In some regions, home care with elements of palliative care is implemented. Unfortunately, these units are created in large regional centres, so that most people who need palliative care, particularly the inhabitants of small towns and villages, cannot get it. Thus, only some patients can get inpatient and outpatient palliative care. As a result, a great number of patients in the terminal stage of cancer and many chronic incurable diseases who require palliative and hospice care, are dying alone at home, suffering from pain, depression and other symptoms of the disease and having no required pain relief, professional care, or social and psychological support.
- Because of lack of funds, the material and technical base of many hospice and palliative care units still does not meet international standards and conditions. The situation is unsatisfactory and can be regarded as a violation of patients' rights.
- Vulnerable palliative care patients require special legal assistance and protection: patients with HIV/AIDS, people without citizenship, immigrants, prisoners, etc. often have problems with access to any form of medical care.
- Another problem faced by palliative care providers is financial difficulties. Today in Ukraine, the results of studies conducted by experts of the All-Ukrainian League on Palliative and Hospice Care have shown that palliative and hospice settings have extremely limited resources and are often unable to provide patients with even the most basic care due to lack of medical equipment, effective anaesthetic, etc.
- According to paragraph 49 of the Constitution of Ukraine, health care is free of charge. Unfortunately, almost all opioids and medical devices are purchased by patients or relatives at their own expense. Maintenance of the quality of life of a terminally ill person requires significant financial costs that may acutely affect the family budget.

General legislation relating to palliative care:

- (1) Legislation relating to palliative care is in process: a special article defining palliative care is in the basic law relating to general health care.

Published national documents relating to palliative care standards and norms:

- (1) National documents relating to palliative care standards and norms are in process.

National Plan or Strategy of Palliative Care:

- (1) A National Plan or Strategy of Palliative Care is in process.

National Cancer Control Strategy:

- (1) There is a National Cancer Control Strategy, but there are financial problems: lack of special equipment, opioids, etc. The provision of palliative care is referred to in the document (but without any concrete proposals/recommendations).

National HIV/AIDS Strategy:

- (1) There is a National HIV/AIDS Strategy but it does not contain a reference to palliative care provision.

National Primary Health Care Strategy:

- There is no information available at this time.

Designated policy maker for the delivery of palliative care services:

- (1) The State policy maker for palliative care in Ukraine is the Institute of Palliative and Hospice Medicine.

Department of Health specific responsibility for the delivery of palliative care services:

- There is no information available at this time.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

- There is no information available at this time.

Opioid legislation/Pain guidelines:

- (1) There is opioid legislation in Ukraine
- Printed pain guidelines are in process: the Institute of Palliative and Hospice Medicine is preparing documents for online publication.

Funding of palliative care services:

- (1) There is a partial payment required for palliative care consultation, hospitalisation and medications.
- Informal payment for palliative care services may be required (not specified).
- Funds for development are provided by international donors.

The International Renaissance Foundation has organised several training courses for medical personnel in Ukraine. Ivano-Frankivsk Hospice formed a training centre, and the Medical Universities began post-graduate training of family doctors

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

- (1) There has been an increase in public awareness or perception of hospice and palliative care.
- (2) Awareness of the importance of palliative care assistance has increased thanks to non-governmental organisation support since 2011. There have been some changes in the structure of public organizations and awareness of the media is changing slowly. However, not all healthcare professionals have a correct understanding of end-of-life care and not all public officials want to implement changes. The importance of palliative care is growing among patients and their relatives. Palliative care activities are also well understood by the clergy, but improvement in this area requires additional education and training.

Major public discussion, debate or controversy about hospice and palliative care:

- (1) In 2010, the Association of Palliative and Hospice Care started the "Artists support hospices" initiative involving charity concerts and other musical fundraising events. In two years, around 2,000 people have attended these events and around 40,000 (estimated) have either heard about them or read about them (on TV or radio, in newspapers, magazines etc).
- (2) Public discussion about hospice and palliative care occurred during the Interfaith Conference on Palliative Care in Kyiv in September 2008 (organised by the Ministry of Health of Ukraine with the participation of all religious faiths in the country): "The role of churches and religious organizations in the development and provision of palliative care" (80 participants: representatives of churches of various denominations of Ukraine) January 30th-February 1st, 2012. It also occurred during the National Seminar on Palliative Care: "Ensuring access to opioid analgesics" in March 2011; the conference relating to publication of the International Human Rights Watch organization report in May 2011. In March 2012, the All-Ukrainian League for Palliative and Hospice Care together with International Renaissance Foundation (Ukrainian Soros Foundation) initiated an information campaign on access to pain relief entitled "Stop the Pain"
- Further public discussions will be held during the creation of a section in the draft program of Health 2020 and in drafting the new national drug control strategy in Ukraine.

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

- (1) In 2008, following meetings with the head of the Ministry of Social Policy, a pilot project on outpatient hospice care commenced in Kiev; this model could be distributed to other regions of Ukraine. Following the conference "Social policy towards incurably ill" in 2012, two new initiatives relating to inpatient and outpatient hospice care were established.
- (2) There have been regular appearances on television and in the media by representatives of the All-Ukrainian League of Palliative and Hospice Care
- A press conference was held with the Ukrainian Independent Information Agency, where journalists were escorted to the palliative care department of Kyiv Hospital № 2: representatives from the media included the newspaper "Young Ukraine", the National Radio Company of Ukraine, the agency "Our product", the newspaper "Pensyniy Kurier", the radio station "Era FM", the TV channel "Gamma", the TV channel "24", the TV channel "Rada", the TV channel "Ukraine", the newspaper "Left Bank", the radio station "Voice of Kiev", the TV channel "Marion", the TV channel "1+1", the TV channel "Novy Kanal", Kiev Regional TV and Radio Company, TV channel "Tonis", and the ICF portal.

<http://www.umj.com.ua/article/18110/dityachi-xospisi-problema-shho-zam-ovchuyetsya>
<http://www.vtvplus.com.ua/lang/ua/news/ukraine/31609-pvmlyona-beznady-no-hvorih-ukrayincv-potrebuyut-hospnoyi-dopomogi.html> (channel "24" video)
<http://www.youtube.com/watch?v=8tJZ2Jg2RHQ> (channel "Rada") <http://play.ukr.net/videos/show/key/44d7offcb2e09775a9b49774734d9acc/promo/1/>
<http://1tv.com.ua/ru/news/2011/10/04/9045>
Article in "Young Ukraine" newspaper
<http://www.umoloda.kiev.ua/number/1955/116/69559/>
Article in "Left Bank" newspaper
http://society.lb.ua/health/2011/10/03/117540_500_tisyach_ukraintsev_ezhegodno_nuzh.html
http://society.lb.ua/health/2011/10/03/117586_Schaste-zhit_dishat_poluchat.html
<http://www.vtvplus.com.ua/lang/ua/news/ukraine/31609-pvmlyona-beznady-no-hvorih-ukrayincv-potrebuyut-hospnoyi-dopomogi.html>
<http://novy.tv/reporter/ukraine/2011/10/03/17/54.html>
Charity event at the Diplomatic Academy
Media Present: First National and Radio Company "Kyiv", 1+1, 5-channel, "Vid-eo News" newspaper "Your Health".
<http://videonews.com.ua/videos/blagoo710.html>
<http://1tv.com.ua/ru/news/2011/10/06/9186>

Hospice or palliative care 'success' stories:

- (1) The event "Social policy for the terminally ill" March 2012 resulted in the production of a number of very interesting reports. For example: "The state and regulatory framework of palliative care in Ukraine", "Improvement of interagency and intersectoral coordination and cooperation in palliative and hospice care", "Ukrainian Orthodox Church as the subject of social policy for terminally patients", "Implementation of hospice as a component of modern social policy", "Social and legal protection of terminally ill and their families", "The concept of quality of life as an indicator of the effectiveness of medical and social policy for the terminally ill" and many others.
- A number of international experts participated in the conference: Prof. A. Prybylka (Katowice University of Economics, Poland); Prof. P. Blendovskyy (Warsaw School of Social Economy, Poland); R. Melnychuk ("Help the Hospices", UK); Prof. Y. Gubsky (Institute of Palliative and Hospice Medicine, Ministry of Health of Ukraine); V. Sultan (Ministry of Social Policy of Ukraine); Rev. Sergei Kosovski (Ukrainian Orthodox Church); Prof. V. Olefir, the first rector of University "Ukraine". It should be noted that the first day of the conference was devoted mainly to palliative care topics (participants discussed the problems of people in the final stage of their life), while on the second day of the event, participants focused on issues of social protection and benefits in the framework of long-term care (including children, elderly with special needs, etc.). It was clear that the terms "palliative care" or "hospice care" cannot be found in the nomenclature of the Ministry of Social Policy.
- Of special interest and discussion was the report of Polish and British colleagues; participants learned not only about the benefits for terminally-ill patients in these countries, but also some practical issues in providing these guarantees (including the practice of cooperation between NGOs and government institutions and raising funds). The conference included representatives from the Ministry of Social Policy – approximately 20 directors of social service centers from different regions of Ukraine – as well as professionals from the research institute of social and labor relations, and representatives from the Ministry of Economy and the Ministry of Health and Health Care Management – approximately 15 physicians and their deputies, also from different regions of Ukraine. Heads of secondary and higher education facilities (specializing not only in nurse training, but also in training on social work and policy) were also present – approximately 10 directors, their deputies, heads of institutes and professors. Other participants included leaders of non-governmental organizations, such as Ukrainian Philanthropists Forum, Caritas Ukraine, Caritas-Spes, "Welfare" (Luhansk region), Kharkov regional foundation "Social Assistance", and Enenko Fund (Lugansk region).

Initiatives seeking the legalisation of euthanasia or assisted dying:

There are no initiatives seeking the legalisation of euthanasia or assisted dying in Ukraine.

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

- (1) Many hospices of different organisational forms need to be developed, with appropriate medical equipment and available/accessible opioids, and suitably educated staff.
- (2) Hopefully, in the next five years there will be a significant growth in palliative care (if all the necessary legal issues are resolved).
- (3) On the condition that reforms in the healthcare system are successful and there is improvement in the economic situation in the country, development of palliative care could be fast. Otherwise it will be a delayed process based on the enthusiasm of a number of highly committed individuals.

Most significant issues facing hospice and palliative care in the next three years:

- (1) Establishing more hospices, and persuading Ukrainian society to consider the problem of palliative care
- (2) Preparation of the required regulatory framework as well as providing information and developing advocacy initiatives with decision-makers and the general public. The All-Ukrainian League on Palliative and Hospice Care (as a leading NGO in this area) is devoted to solving these problems through hosting conferences, congresses, and round-table meetings.
- (3) Immediate legalisation from an Order of the Minister of Health Care of Ukraine providing palliative care in the country; increasing the quantity of hospices, departments of palliative care and home palliative care services; immediate legislation through a statement by the Cabinet of the Ministers of Ukraine on the use of opioids in the healthcare system; registration of oral morphine.

Implications for palliative care relating to the current economic crisis:

- (1) More emphasis should be given to local fundraising and grass-roots initiatives.
- (2) Lack of public funds; reduction in charitable contributions; reduction in private initiatives for creating palliative care institutions.
- (3) In a situation of economic crisis, it is impossible to fully introduce palliative care into the healthcare system.

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Lukas Radbruch. July-August 2011. "European insight: Access to opioids in Ukraine: an international meeting in Kiev". *European Journal of Palliative Care*, Volume 18 Number 4

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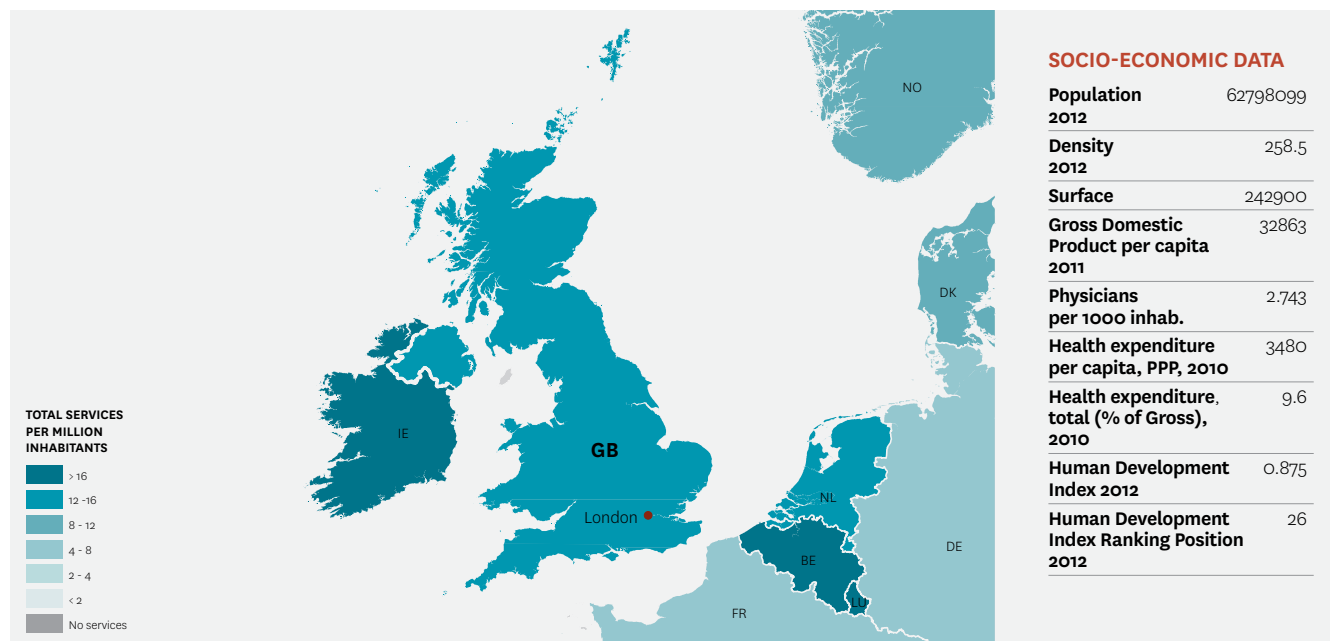
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¹ Information collected by the EAPC Task Force predominantly from the Eurobarometer Survey (2012) and the Facts Questionnaire (2012); other sources include data collected for the First Edition of the EAPC Atlas of Palliative Care in Europe (2007) and personal communication. The information was peer reviewed in 2012.



Palliative Care Services

| | ADULT SERVICES (BEDS) |
|---|--|
| Volunteer hospice team | 0 |
| Hospital palliative care support team | 308 |
| Home palliative care support team | 337 services , 305 providers |
| Mixed palliative care support team | 104 |
| Palliative care units in tertiary hospitals | 31 (248 beds) |
| Palliative care units in non-tertiary hospitals | 0 |
| Inpatient hospice | 189 units , 166 providers (2908 beds) |
| Day hospice/day care centre | 272 services (211 providers) |

COMMENT/SOURCES ABOUT PALLIATIVE CARE SERVICE

Primary sources of information of the data listed above:

Help the Hospices/UK Directory of Hospice and Palliative Care Services (data collected October 2011).

Additional comments:

- Help the Hospices/UK Directory of Hospice and Palliative Care Services does not routinely collect data on volunteer services.
- Together for Short Lives (<http://www.togetherforshortlives.org.uk/>)
- The number of home palliative care support teams includes services defined as 'Home care' and 'Hospice at Home'. 'Home Care' is defined as a community-based advisory service provided by a nursing or multidisciplinary team. 'Hospice at Home' is defined as an extended nursing care service that provides hands-on care, respite support or crisis intervention for up to 24 hours. This team includes at least one clinical nurse specialist. A single service may contain more than one home care team, hence provision of number of services and number of providers.
- There is no differentiation made between services provided by tertiary and non-tertiary hospitals. The information provided here indicates designated palliative care beds in hospitals (tertiary or non-tertiary).
- Inpatient hospice services provided by Marie Curie Cancer Care and Sue Ryder have been counted as one provider with multiple service locations - this principle is applied throughout the data (e.g. for day care, home care, etc) - this is because other charities providing inpatient hospice services are counted as one provider (for example, "Acorns" which has three sites).
- A single service may contain more than one day centre, hence provision of services and providers offering those services.

Palliative care services for children:

There are ten paediatric hospital palliative care support teams, 46 paediatric home palliative care support teams (39 providers), 241 paediatric palliative care units in tertiary hospitals, 42 paediatric inpatient hospice units (30 providers and 334 beds), and 31 paediatric day care services (24 providers).

Development

HOSPICE AND PALLIATIVE CARE MILESTONES PRIOR TO 2006

| | |
|-------------|--|
| 2000 | The NHS Cancer Plan is published, promising £50m additional investment per annum for specialist palliative care. |
| 2004 | The National Institute for Clinical Excellence guidance on Improving Supportive and Palliative Care for Adults with Cancer set out the services that should be available and each of the 34 cancer networks in England produces an action plan to implement this guidance over the next few years. This provides the basis for commissioners to undertake local needs assessment to see how closely current services match what should be available. It also provides a basis for peer review of services and for the development of clear commissioning and funding arrangements for palliative care. |
| 2004 | The End of Life Care Programme for England is launched with a budget of £12 million over three years. |
| 2004 | Help the Hospices marks the publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organisation of palliative care) by printing the report in the UK, circulating it at the Korea World Summit of National Associations for Palliative Care, and making it available at the European Health Forum. |

EAPC Palliative Care Euro-Barometer 2005

DEVELOPMENTS IN HOSPICE AND PALLIATIVE CARE SINCE 2006

Most significant changes in hospice and palliative care:

The way palliative care services are commissioned by the local health authorities.

Overall progress in hospice and palliative care:

Progress in hospice and palliative care has improved.

Development of hospice and palliative care in different health and social care settings:

- Hospitals: There has been development.
- Nursing homes: There has been development.
- Residential homes for the elderly: Hospice and palliative care is developing in this area.
- Other com. set: Hospice and palliative care is developing in sheltered housing.

Expansion from a focus on cancer patients to address the needs of 'non-cancer' patients:

There has been an expansion *from a focus on cancer patients to address the needs of 'non-cancer' patients.*

Perceived barriers to the development of hospice and palliative care:

- Financial Cutbacks which have affected Hospices
- Lack of social Care
- Societal attitude to death and dying

Perceived opportunities for the development of hospice and palliative care:

- Increased collaboration between health and social care
- More evidence-based practice in hospice and palliative care
- The work of the End of Life Care Programmes Board (NHS)

Other issues relevant to the development of hospice and palliative care:

There is no information available at this time.

Vitality

THE VITALITY OF PALLIATIVE CARE

National Associations of Palliative Care:

- The National Council for Palliative Care (NCPC) was formed in 1991 as The National Council for Hospice and Specialist Palliative Care Services; the council has a website (<http://www.ncpc.org.uk/>) but is not representative of the whole country (it covers England, Wales and Northern Ireland only).
- <http://www.palliativecarescotland.org.uk/> is the only representative in Scotland.
- Hospices Cymru (HC) (<http://www.helpthehospices.org.uk/our-services/running-your-hospice/policy/hospices-cymru/>) is representative of Wales.
- Help the Hospices was formed in 1984; it has a website (<http://www.helpthehospices.org.uk>) and is representative of the whole country.
- "Together for Short Lives, Children's Hospices UK" merged with ACT to become "Together for Short Lives" in October 2011; the organisation has a website (<http://www.togetherforshortlives.org.uk/>) and is representative of the whole country.
- There are a number of other national associations representing different professional groups within the UK. These include the Association for Palliative Medicine of Great Britain and Ireland, and the Association for Paediatric Palliative Medicine.

Directory or catalogue of palliative care services:

- The Hospice and Palliative Care Directory: UK and Ireland (2009-2010) was first published by Help the Hospices in 2002. The directory was previously published by St Christopher's Hospice, London (last edition 2009-2010). Online first edition 2002 (continuously updated online) (<http://www.helpthehospices.org.uk/findahospice>).

Congresses, scientific meetings or scientific journals in palliative care:

- The National Palliative Care Congress is held biannually (attended by an unknown number of participants). See website: (<http://www.pccongress.org.uk/>).
- The International Cardiff Conference on Paediatric Palliative Care is held biannually (attended by an unknown number of participants).
- Help the Hospices host a multi-professional conference on a biannual basis (attended by approximately 700 participants).
- BMJ Supportive and Palliative Medicine is published quarterly (and continuously online).
- Palliative Medicine is published eight times year (and continuously online: <http://pmj.sagepub.com/>).

Palliative care research capacity:

There are a number of palliative care academic centres, professorial chairs etc. A random selection is listed below.

- Centre for the Promotion of Excellence in Palliative Care (<http://www.dmu.ac.uk/about-dmu/schools-and-departments/school-of-nursing-and-midwifery/cpep/cpep.aspx#moreLinks>)
- Cicely Saunders Institute (<http://www.cicelysaundersinternational.org/>)
- International Observatory on End of Life Care (<http://www.lancs.ac.uk/shm/research/ioelc/index.php>)
- Marie Curie Palliative Care Research Unit (MCPCRU) (<http://www.mariecurie.org.uk/research/>)
- Palliative Care Research Society (<http://www.pcrs.org.uk/>)
- Sobell Study Centre (<http://www.sobell-house.org.uk/>)
- The Louis Dundas Centre for Children's Palliative Care (<http://www.gosh.org/gen/louis-dundas-centre/>)
- The Sue Ryder Centre for the Study of Supportive, Palliative and End of Life Care (<http://www.nottingham.ac.uk/nmp/research/groups/srcc/index.aspx>)
- Palliative care researchers include staff at hospices as well as academic and research centres.

Palliative care collaboration:

- While there is no single body specifically designated to facilitate and coordinate hospice twinning/partnerships, there is a wealth of knowledge and support available from individuals and organisations. 19 UK hospices have formed partnerships with 26 hospice/palliative care services overseas – there is evidence of many more informal arrangements including training and exchange visits.
- Worldwide Palliative Care Alliance (WPCA) - The WPCA is a global action network focusing exclusively on hospice and palliative care development worldwide. Its members are national and regional hospice and palliative care organisations and affiliate organisations supporting hospice and palliative care (www.thewpca.org)
- The ATOME project aims to improve access to opioids across Europe. A consortium of 10 academic institutions and public health organisations is working to help governments in 12 countries identify and remove barriers that prevent people from accessing medicines that could improve end of life care, alleviate debilitating pain and treat heroin dependence. The 12 target countries of the ATOME project are Bulgaria, Cyprus, Estonia, Greece, Hungary, Latvia, Lithuania, Poland, Serbia, Slovakia, Slovenia and Turkey (www.atome-project.eu)
- Sierra Leone – A Health Systems Development (five-year) DfID-funded project intended to train community health workers and community volunteers in eight districts; working to integrate palliative care into national policy.
- African Palliative Care Association (five-year) DfID-funded project working in six countries - Ethiopia, Kenya, Malawi, Rwanda, Tanzania, and Zambia supporting national associations to address key barriers to opioid availability, advocacy training and training doctors as trainers in morphine use.
- International Children's Palliative Care Network (five-year) DfID-funded project to develop children's palliative care in India and Malawi; supporting the national associations to conduct advocacy on palliative care for children.
- E-hospice - Launching in October 2012, e-hospice is a free website offering real-time international news and intelligence on hospice, palliative and end of life care. Help the Hospices is working closely with regional and national hospice and palliative care organisations worldwide on the development of e-hospice. A wide range of hospice and palliative care organisations are involved in this initiative.
- Other collaborations (not connected with Help the Hospices) include:
 - Hospices of Hope, Romania: www.hospicesofhope.co.uk
 - Hospice Africa: <http://hospice-africa.merseyside.org>
 - Cairdeas - international palliative care: <http://cairdeas.org.uk/home.htm>
 - Palliative Care Works: <http://www.palliativecareworks.org>
 - African Palliative Care Association, University of Makerere and University of Edinburgh - THET multi-country partnership: www.thet.org/hps/news/health-partnership-scheme-grant-winners-announced
- There are a variety of groups and organisations that have pioneered the development of palliative care in the UK. Hospices have been a significant provider of care and also generated awareness and understanding of palliative care among professionals and the public. National associations and other organisations have supplemented this and raised awareness and understanding among policy makers which has led to the development of the various end of life care strategies across the UK.
- In 2010, the Economist Intelligence Unit developed a methodology to rank end of life care provision among 40 countries across the world. The United Kingdom came first in the ranking and the Unit specifically marked out hospices for their contribution (http://www.eiu.com/site_info.asp?info=qualityofdeath_lienfoundation&page=noads)
- There are two hospices that are often referred to as pioneers of palliative care in the UK. The first is St Joseph's Hospice, Hackney, London (1905) which was established by the Sisters of Charity who also pioneered a number of other hospices across the world; this was where the late Dame Cicely Saunders developed many of the principles that served as a foundation at St Christopher's Hospice, Sydenham, London (1967). This second hospice is recognised across the world as the birth place of modern hospice care and serves as a focus for hospice and palliative care across the UK and the world.
- Helen House, Oxford, England (1982) pioneered the development of hospice care for children and is often cited as the first such service in the world. Rachel House (Scotland) was opened in 1994, Ty Hafan inn (Wales) was opened in 1999 and Horizon House (Northern Ireland) was opened in 2004. One of the greatest challenges at present is the increasing number of young adults with a palliative care need. In 2004, Douglas House, Oxford, England opened to provide palliative care for young adult; it has been followed with the development of similar services across the UK.

- Hospice Care Week is an annual awareness-raising week led by Help the Hospices and supported by hospices across the United Kingdom. The week includes activities to promote and mark World Hospice and Palliative Care Day. (<http://www.besurprised.org.uk/>)
- "Voices for Hospices" is an event that takes place on World Hospice and Palliative Care Day biannually. Simultaneous events take place across the world to raise awareness about (and funds for) hospice and palliative care. This is coordinated by the Worldwide Palliative Care Alliance, which is facilitated by Help the Hospices. (<http://www.worldday.org/voices-for-hospices/>)
- A wide range of events are organised locally across the United Kingdom (without a national point of coordination).

Worldwide palliative care alliance level of development:

4B (Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision).

Education

DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING SINCE 2006

General developments in palliative care education and training initiatives:

- E-Learning
- Palliative care education and training initiatives among nursing home staff
- General nursing staff learning End of Life Care tools

Specific developments in under-graduate palliative care education initiatives:

- Medicine: There is no information available at this time.
- Nursing: N/A
- Social work: Not much development but change is on the way (although the picture is patchy).
- Other professions: There is no information available at this time.

Specific developments in post-graduate palliative care education initiatives:

- Medicine: There is no information available at this time.
- Nursing: There is no information available at this time.
- Social work: Not much development but change is on the way (although the picture is patchy).
- Other professions: There is no information available at this time.

Translation of palliative care documents or other materials:

The immigration of people from Eastern Europe (particularly Poland) has meant local information has needed to be translated.

Initiatives to develop healthcare professional leadership in palliative care:

Initiatives to promote healthcare professional leadership in palliative care have been developed at Lancaster University.

Officially recognized medical certification:

- In the UK, the specialty of palliative medicine exists in which doctors are required to undertake four to five years of specialist training (<http://www.jrcptb.org.uk/specialties/ST3-SpR/Pages/Palliative-Medicine.aspx>)
- Specialist nurses need a postgraduate qualification in palliative care (one to two years duration).

Capacity of palliative care workforce training in Universities and Medical Schools:

- The UK has 31 medical schools (www.medschools.ac.uk/%2fStudents%2fUK-MedicalSchools%2fPages%2fUK-Medical-Schools-A-Z.aspx).
- The Higher Education Statistics Agency (who collect data on the number of staff/students in higher education) do not have specific data on "Professors of Palliative Medicine".

Opioids

DEVELOPMENTS IN PAIN AND SYMPTOM MANAGEMENT SINCE 2006

Developments/opportunities/barriers relating to the availability of essential medications:

A wider range of opioids are available and in different forms.

Developments/opportunities/barriers relating to the accessibility of essential medications:

A wider range of opioids are available and in different forms.

Developments/opportunities/barriers relating to the affordability of essential medications:

There is no information available at this time.

Initiatives to change regulations that may restrict physician or patient access to pain relief:

here is no information available at this time.

Initiatives to promote attitudinal change in relation to 'opiophobia':

The "Shipman effect" is reducing for GPs.

Initiatives that examine access to opioid medication for economically disadvantaged persons:

There have been initiatives that examine access to opioid medication for the prison and Roma populations.

Initiatives that consider access to essential medication as a legal and human right:

Not necessary in the UK.

Development of an advocacy framework for integrating palliative care into the health care system:

There has been development of an advocacy framework for integrating palliative care into the health care system.

Strategies to improve political awareness and government recognition of palliative care:

The publication "Dying Matters" has improved political awareness and government recognition of palliative care.

Palliative care funding initiatives by government, private/voluntary organisations, NGOs, donors:

- There has been a review of palliative care funding.
- There has been some funding provided to develop palliative care training initiatives for social workers..

Involvement with the European Union in relation to hospice and palliative care initiatives:

Involvement with the European Union has mainly been in the form of research partnerships.

Development of initiatives framing palliative care as a 'human right':

Palliative care as a 'human right' is enshrined in the Mental Capacity Act.

General legislation relating to palliative care:

There is no information available at this time.

Published national documents relating to palliative care standards and norms:

- England - Adults - <http://www.nice.org.uk/newsroom/pressreleases/End-OfLifeCareQualityStandard.jsp>
- Scotland - Adults - <http://www.palliativecarescotland.org.uk/content/publications/?cat=6>
- Wales - Adults and children's - <http://www.wales.nhs.uk/palliativecare/>
- Standard in process: England, Together for Short Lives has been developed based on the children's palliative care pathway and can be viewed at: <http://www.act.org.uk/news.asp?itemid=1783&itemTitle=New+standards+-framework+for+children%27s+palliative+care§ion=94§ionTitle=News>. The development of further standards for children's hospice and palliative care is being explored by the National Institute for Health and Clinical Excellence, Together for Short Lives and the Department of Health.

National Plan or Strategy of Palliative Care:

- England - The End of Life Care Strategy was published in 2008 to drive improvements in palliative and end of life care. The strategy was supported with over £150million in additional funds and can be viewed at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277
- Scotland - The Living and Dying Well action plan for palliative and end of life care was published in 2008. The action plan can be viewed at: <http://www.scotland.gov.uk/Publications/2008/10/01091608/0>
- Wales - The All Wales Palliative Care Planning Group Report was published in 2008 and made recommendations for improving services and provision. The Report can be viewed at: <http://www.wales.nhs.uk/sites3/Documents/831/pcpg%20report%20final%20June%2008.pdf>
- Northern Ireland - The Living and Dying Matters Strategy was published in 2010 to drive improvements in palliative and end of life care. The strategy can be viewed at: <http://www.dhsspsni.gov.uk/class?st=Strategies%20and%20Action%20Plans>

Policy

DEVELOPMENT OF PALLIATIVE CARE POLICY SINCE 2006

Most important legal or policy changes affecting the development of hospice and palliative care:

- The Mental Capacity Act 2005 (came into force in 2007)
- The Health Reform Act

The impact of these policy changes and ways in which they have been important:

Improved protection of vulnerable people; safeguarding policy has been improved.

Development of a national palliative care consensus:

The NICE guidelines on Supportive Care for Cancer Patients has had a major effect on the role of specialist social workers.

Significant meetings with stakeholders and policy makers to develop palliative care strategies:

There have been many such meetings (particularly between health and social care representatives).

In 2008, The End of Life Care Strategy was published in England to drive improvements in palliative care; The Living and Dying Well Action Plan for Palliative and End of Life Care was published in Scotland (also in 2008)

National Cancer Control Strategy:

- England: "Improving outcomes: a strategy for cancer" in 2011 provided a strategy for improving outcomes for people with cancer and makes reference to palliative care: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123371
- Scotland: "Better cancer care: an action plan" published in 2008 provided a comprehensive plan to improve cancer care and makes reference to palliative care: <http://www.scotland.gov.uk/Publications/2008/10/24140351/o>
- Wales: "Designed to tackle cancer in Wales" published in 2006 outlines the Assembly Government's policy aims and strategic direction to tackle cancer and makes reference to palliative care: <http://www.wales.nhs.uk/documents/Designed-to-tackle-Cancer.pdf>
- Northern Ireland: "A cancer control programme for Northern Ireland" published in 2008 refocuses efforts to improve cancer care and makes reference to palliative care: <http://www.cancerni.net/publications/cancercontrolprogramme>

National HIV/AIDS Strategy:

- England: "Better prevention, better services, better sexual health - The national strategy for sexual health and HIV" published in 2001 was the first strategy of its kind. The strategy had no reference to palliative care but can be viewed at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003133. Organisations from across the HIV and AIDS sector are calling on the Department of Health to establish a new strategy.
- Scotland: "HIV action plan in Scotland" was first published in 2009 and expires in 2014. The plan has no reference to palliative care but can be viewed at: <http://www.scotland.gov.uk/Resource/Doc/293178/0090440.pdf>
- Wales: "National care pathways and service specification for testing, diagnosis, treatment and supportive care" was published in 2009. The document makes reference to palliative care and can be viewed at: <http://www.wales.nhs.uk/sites3/page.cfm?orgid=895&pid=47152>
- Northern Ireland: "Sexual health promotion strategy and action plan" was first published in 2008 and expires in 2013. The plan has no reference to palliative care but can be viewed at: http://www.dhsspsni.gov.uk/dhssps_sexual_health_plan_front_cvr.pdf

National Primary Health Care Strategy:

- England: There is no primary health care strategy in existence.
- Scotland: "Delivering quality in primary care national action plan" published in 2010 makes no reference to palliative care provision: <http://www.scotland.gov.uk/Resource/Doc/321597/0103382.pdf>
- Wales: "Primary and community services strategic delivery programme" published in 2010 makes reference to end of life care: <http://www.wales.nhs.uk/sitesplus/documents/829/Setting%20the%20direction.pdf>
- Northern Ireland: "Primary care strategic framework" published in 2005 makes no reference to palliative care provision: http://www.dhsspsni.gov.uk/index/hss/primary_care-strategy.htm

Designated policy maker for the delivery of palliative care services:

- England: Professor Sir Michael Richards is based at the Department of Health and led the development of the "Cancer Reform Strategy" and the "End of Life Care Strategy". Sir Alan Craft is a paediatric expert and has contributed to the development of government policy covering children's hospice and palliative care.
- Wales: Baroness Iloria Finlay is a palliative care expert and leads the All Wales Palliative Care Implementation Board.

Department of Health specific responsibility for the delivery of palliative care services:

Local Primary Care Trusts have responsibility for the commissioning of hospice and palliative care services.

Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care:

- England: The Care Quality Commission (CQC) is the regulator for health and social care services and charged with maintaining essential standards of safety and quality. Hospices came under the remit of the CQC in October 2010. The CQC has produced notes for its assessors and inspectors: http://www.cqc.org.uk/sites/default/files/media/documents/rp_poc1b-1c2b3b4b_100487_20110726_v1_00_supporting_note_eol_for_external_publication.pdf. The NHS Outcomes Framework includes a reference to meeting the needs of people at the end of life: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_123138.pdf. The Adult Social Care Outcomes Framework does not currently include a reference to meeting the needs of people at the end of life.
- Scotland: The Care Commission regulates hospice care in Scotland.
- Wales: The Healthcare Inspectorate Wales (HIW) and the Care and Social Services Inspectorate Wales (CSSIW) regulate hospice care in Wales.
- Northern Ireland: The Regulation and Quality Improvement Authority regulates hospice care in Northern Ireland.

Opioid legislation/Pain guidelines:

- Opioids: There is no information available at this time.
- Pain guidelines are available online:
England: <http://guidance.nice.org.uk/CG140>
Scotland: <http://www.knowledge.scot.nhs.uk/pain.aspx>
Northern Ireland: <http://www.gain-ni.org/Publications/Guidelines/Gain%20pain%20final.pdf>

Funding of palliative care services:

- There is no payment required for palliative care consultation, hospitalisation or medications.
England: In June 2012, the Coalition Government announced a £60 million Capital Grants Fund to be released over two years. Both NHS and independent hospices providing care to adults or children can apply for grants to enhance the hospice environment. Further details of the grants fund can be viewed at: <http://www.dh.gov.uk/health/2012/05/hospicefunding/>
- In addition, there are considerable funds made available to hospice and palliative care providers each year. The funds come from a number of sources. In the year ending March 2010, hospices raised over £550 million from the communities they serve. Other organisations such as national associations like Help the Hospices or grant making bodies make funds available for palliative care.

The All Wales Palliative Care Planning Group Report was published in 2008, making recommendations for improving services and provision. In 2010, The Living and Dying Matters Strategy was published in Northern Ireland

Socio-cultural

CHANGE IN SOCIO-CULTURAL, ETHICAL, MORAL ATTITUDES SINCE 2006

Change in public awareness or perception of hospice and palliative care:

There has not been much change in public awareness or perception of hospice and palliative care.

Major public discussion, debate or controversy about hospice and palliative care:

The "Dying Matters" campaign including the appointment of a number of hospice and palliative care "Champions".

Initiatives that seek to broaden awareness and understanding of hospice and palliative care:

The End of Life Care Newsletter.

Hospice or palliative care 'success' stories:

The public death of Jane Goody (an actress who had cervical cancer) raised issues of screening and preparing children for the death of a parent.

Initiatives seeking the legalisation of euthanasia or assisted dying:

- A number of bills about assisted suicide have been discussed in the House of Lords.
- The Director of Public Prosecutions has provided some guidelines for the prosecution of people who aid assisted suicide by accompanying people to Switzerland to die (where it is legal)

Future

THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

The future of hospice and palliative care development:

Hospices are in need of additional financial support but are subjected to increased bureaucracy. The ageing population will put great strain on both health and community services and there is concern about the expected rise in dementia patients.

Most significant issues facing hospice and palliative care in the next three years:

Palliative care training for social care professionals.

Implications for palliative care relating to the current economic crisis:

Retaining the resources necessary to provide holistic care (giving people time and safety at the end of the life).

In June 2012, the Coalition Government announced a £60 million Capital Grants Fund to be released over two years. Both NHS and independent hospices providing care to adults or children can apply for grants to enhance the hospice environment

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3. Additional Information

Annex 1

GLOSSARY

Definitions and terms used in this publication have been extracted from The EAPC White Paper on *Standards and Norms for Hospice and Palliative Care* (European Journal of Palliative Care, 2009; 16(6) pp. 278-289). The document provides a variety of definitions, an overview of the philosophy of palliative care and recommendations for the number of services, including staffing and service provision in different settings.

Palliative Care: Palliative care is the active, total care of the patient whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.

Hospice Care: Hospice care is for the whole person, aiming to meet all needs – physical, emotional, social and spiritual. At home, in day care and in the hospice, care is provided for the person who is facing the end of life and for those who love them. Staff and volunteers work in multi-professional teams to provide care based on individual need and personal choice, striving to offer freedom from pain, and dignity, peace and calm.

Supportive Care: Supportive care is the prevention and management of the adverse effects of cancer and its treatment. This includes physical and psychosocial symptoms and side-effects across the entire continuum of the cancer experience, including the enhancement of rehabilitation and survivorship.

End-of-life care: End-of-life care may be used synonymously with palliative care or hospice care, with end of life understood as an extended period of one to two years during which the patient/ family and health professionals become aware of the life-limiting nature of their illness.

Terminal Care: Terminal care is an older term that has been used for comprehensive care of patients with advanced cancer and restricted life expectancy.

Respite Care: Family members or other primary caregivers caring for a palliative care patient at home may suffer from the continuous burden of care. Respite care may offer these patients and their caregivers a planned or unplanned break.

Palliative Care Approach: The palliative care approach is a way to integrate palliative care methods and procedures in settings not specialised in palliative care. This includes not only pharmacological and non-pharmacological measures for symptom control, but also communication with patient and family as well as with other healthcare professionals, decision-making and goal-setting in accordance with the principles of palliative care.

General Palliative Care: General palliative care is provided by primary care professionals and specialists treating patients with life-threatening diseases who have good basic palliative care skills and knowledge.

Specialist Palliative Care: Specialist palliative care is provided by specialised services for patients with complex problems not adequately covered by other treatment options.

Patients: Palliative care is not restricted to predefined medical diagnoses, but should be available for all patients with life-threatening diseases.

Disease Stage: There is no predefined time point in the course of the disease marking the transition from curative to palliative care.

Children and Adolescent: Palliative care for children represents a special, albeit closely related field, to adult palliative care. Palliative care for children begins when the illness is diagnosed, and continues regardless of whether or not the child receives treatment directed at the disease. The unit of care is the child and family.

Access to services: Services should be available to all patients, wherever and whenever they require them, without delay.

Continuity of Care: Continuity of care throughout the disease trajectory and across the different settings in the healthcare system is a basic requirement of palliative care.

Preferred place of Care: Most patients want to be cared for in their own homes, if possible until the time of death. In contrast to this, the place of death for most patients is the hospital or nursing home.

Locations of Care: Palliative treatment, care and support are provided at home, in nursing homes, in residential homes for the elderly, in hospitals and in hospices, or in other settings if required.

Palliative Care Networks: Regional networks integrating a broad spectrum of institutions and services, and effective co-ordination, will improve access to palliative care and increase quality as well as continuity of care.

Staff in specialist Palliative Care services: Services that are not specialised in palliative care can use a palliative care approach or deliver basic palliative care, even when this can only be done by one professional category, or even by one individual (for example, a general practitioner working alone), if they have access to support from an interdisciplinary team.

Voluntary work: Specialist palliative care services should include volunteers or collaborate with volunteer services.

Palliative Care Unit: Palliative care units (PCUs) provide specialist inpatient care. A palliative care unit is a department specialised in the treatment and care of palliative care patients. In some countries, palliative care units will be regular units of hospitals, providing crisis intervention for patients with complex symptoms and problems; in other countries, PCUs can be freestanding institutions, providing end-of-life care for patients where home care is no longer possible. The aim of these palliative care units is to offer patient and carers social support in a way that allows for discharge or transfer to another care setting. These units may also provide support for appropriate patients cared for in care homes.

PCUs require a highly qualified, multidisciplinary team. Staff members in palliative care units are supposed to have specialist training. The core team consists of doctors and nurses. The extended team comprises of relevant associated professionals, such as psychologists, physiotherapists, social workers or chaplains. These professions should be included in the team or work in close liaison with it. There should be a dedicated input from these professionals, or at least ready access to them should be warranted.

Inpatient Hospice: A palliative care unit in an inpatient hospice admits patients in their last phase of life, when treatment in a hospital is not necessary and care at home or in a nursing home is not possible. A palliative care unit in an inpatient hospice requires a multi-professional team that cares for patients and their relatives using a holistic approach. Nursing staff should encompass at least one, preferably 1.2 nurses per bed. A physician trained in palliative care should be available 24 hours a day. There should be dedicated input from an extended team comprising of social workers, psychologists, spiritual carers, physiotherapists, dietitians, speech and language therapists and occupational therapists, as well as voluntary workers.

Hospital Palliative Care support team: Hospital palliative care support teams provide specialist palliative care advice and support to other clinical staff, patients and their families and carers in the hospital environment. They offer formal and informal education, and liaise with other services in and out of the hospital. Hospital palliative care support teams, in the first instance, offer support to healthcare professionals in hospital units and polyclinics not specialised in palliative care.

A hospital palliative care support team is composed of a multi-professional team with at least one physician and one nurse with specialist palliative care training. Home palliative care support team: Home palliative care teams provide specialised palliative care to patients who need it at home and support to their families and carers at the patient's home. They also provide specialist advice to general practitioners, family doctors and nurses caring for the patient at home. The core team of a home palliative care team consists of four to five full-time professionals and comprises of physicians and nurses with specialist training, a social worker and administrative staff.

“Hospital at home”: The Hospital at home provides hospital-like care for the patient at home.

Volunteer hospice team: A volunteer hospice team offers support and befriending to palliative care patients and their families in times of disease, pain, grief and bereavement. The volunteer hospice team is part of a comprehensive support network and collaborates closely with other professional services in palliative care. The volunteer hospice team comprises of specially trained voluntary hospice workers with at least one professional coordinator.

Day Hospice: Day hospices or day-care centres for palliative care are spaces in hospitals, hospices, PCUs or the community especially designed to promote recreational and therapeutic activities among palliative care patients. A day hospice or day-care centre for palliative care is staffed by a multi-professional team supplemented by voluntary workers. It is recommended that there are two nurses present during opening hours, with at least one specialist palliative care nurse for every seven daily attendees. A qualified physician should be directly accessible in case of need. Ready access to other professionals, such as physiotherapists, social workers or spiritual care workers, should be obtained. Palliative outpatient clinic: Palliative outpatient clinic offers consultation for patients living at home who are able to visit the clinic.

Annex 2

EUROBAROMETER SURVEY

Qualitative information on the background situation of palliative care in each country has been generated by the Eurobarometer Survey. In the *Eurobarometer Survey*, the provision of palliative care is considered within the wider milieu of health care policy, as well as social, ethical and cultural factors



European Association for Palliative Care Onlus (EAPC)

*The EAPC Task Force on the
Development of Palliative Care in Europe*

Palliative Care Eurobarometer Survey 2011

Current issues in the development of hospice and palliative care in Europe: the vision of national organizations

Dear Colleague,

The *European Association for Palliative Care (EAPC) Task Force on the Development of Palliative Care in Europe* is to produce a Second Edition of the *EAPC Atlas of Palliative Care in Europe*, which will provide a reliable and comprehensive analysis on the development of the discipline within each European country, and generate an ‘evidence base’ of clear and accessible research-based information concerning current provision across the region. As a valued contributor to the development of palliative care in Europe, the Task Force would like to take this opportunity to invite you to collaborate with us on this new project. The Task Force has refined and improved the format of the original *Eurobarometer Survey* and we would be extremely grateful if you could complete this newly updated version. Many thanks in advance for your help with this matter.

Professor Carlos Centeno, Chair, EAPC Task Force on the development of palliative care in Europe



Universidad
de Navarra

Thank you for agreeing to take part in this survey.

We are seeking information from EAPC collective members, national associations and key individuals or organisations involved in palliative care across a total of 53 European countries:

| | | | | |
|--------------------|----------------|-------------|-----------------------|----------------|
| Albania | Czech Republic | Israel | Norway | Spain |
| Andorra | Denmark | Italy | Poland | Sweden |
| Armenia | Estonia | Kazakhstan | Portugal | Switzerland |
| Austria | Finland | Kyrgyzstan | Republie of Moldova | Tajikistan |
| Azerbaijan | France | Latvia | Republic of Macedonia | Turkey |
| Belarus | Georgia | Lithuania | Romania | Turkmenistan |
| Belgium | Germany | Luxembourg | Russian Federation | Ukraine |
| Bosnia Herzegovina | Greece | Malta | San Marino | United Kingdom |
| Bulgaria | Hungary | Monaco | Serbia | Uzbekistan |
| Croatia | Iceland | Montenegro | Slovakia | |
| Cyprus | Ireland | Netherlands | Slovenia | |

This survey aims to provide a ‘barometer’ of the current situation of palliative care in Europe as well as insights into current issues and debates on the subject.

Please answer *all* the questions as accurately as possible. Make use of the space for comments to clarify your information and to describe distinct characteristics of services/health organizations in your country wherever you consider it appropriate to do so. Please refer to authors, full references and sources of information **since January 2006** whenever possible.

If you have any questions about the completion of this survey, please do not hesitate to contact the EAPC Task Force Research Associate, Dr. Thomas Lynch:
t.lynch@lancaster.ac.uk

If you wish to contact the European Association for Palliative Care for further information on the background to this project, please do not hesitate to contact Dr. Amelia Giordano at the EAPC Head Office:
Amelia.Giordano@istitutotumori.mi.it

1. BACKGROUND INFORMATION

1.1 What is your full name?

1.2 What is the name of the palliative care association or institution that you are representing in the survey?

1.3 What is your position in that association or institution?

1.4 How long have you been employed in that position?

1.5 What are your contact details?

- Address:
- Telephone/fax number:

- E-mail address:

2. QUESTIONS ON THE CURRENT STATE OF DEVELOPMENT OF PALLIATIVE CARE

2.1 What are some of the most significant changes that have taken place in the hospice and palliative care sector in your country since January 2006? What has contributed to those changes?

2.2 How would you evaluate the overall progress in hospice and palliative care in your country since January 2006? Please indicate with an 'X' the statement that best describes this progress from the three options given below. Since January 2006, palliative care in my country:

- | | |
|--------------------------------------|--------------------------|
| (i) has improved | <input type="checkbox"/> |
| (ii) has remained very much the same | <input type="checkbox"/> |
| (iii) has got worse | <input type="checkbox"/> |

2.3 Since January 2006, how has the provision of hospice and palliative care developed in the following different health and social care settings?

- Hospitals
- Nursing homes
- Residential homes for the elderly
- Other community settings

2.4 Since January 2006, has palliative care been expanded in your country from a focus on cancer patients to address the needs of ‘non-cancer’ patients? (For example, people living with dementia, stroke, heart failure, HIV/AIDS, TB, etc.)

2.5 Please list in order of importance the three main *barriers* to the development of palliative care in your country at the present time:

- (i)
- (ii)
- (iii)

2.6 Please list in order of importance the three main *opportunities* for the development of palliative care in your country at the present time:

- (i)
- (ii)
- (iii)

2.7 Please comment on any other issues that have been relevant to the development of palliative care in your country since January 2006.

3. QUESTIONS ON POLICY

3.1 What have been the most important legal or policy changes affecting the development of hospice and palliative care in your country since January 2006?

3.2 What has been the impact of these policy changes and in what ways have they been important?

3.3 To what extent has a national palliative care consensus been developed in your country since January 2006? (For example, through palliative care frameworks, standards, guidelines or legislation)

3.4 Have any significant national meetings with stakeholders and policy makers to develop national palliative care strategies taken place in your country since January 2006?

3.5 Has an advocacy framework been developed for integrating palliative care into the national health care system in your country since January 2006?

3.6 What strategies have been used to improve political awareness and government recognition of palliative care amongst health care policy makers in your country since January 2006?

3.7 Have there been any special palliative care funding initiatives by government, private/voluntary palliative care organisations, NGOs or donors since January 2006?

3.8 Has there been any involvement between your country and the European Union in relation to hospice and palliative care initiatives since January 2006?

3.9 To what extent have initiatives framing palliative care as a 'human right' developed in your country since January 2006?

4. ESSENTIAL MEDICATION FOR PAIN AND SYMPTOM MANAGEMENT

4.1 Please comment on any developments in your country since January 2006 relating to the:

- Availability of essential medications
- Accessibility of essential medications
- Affordability of essential medications

4.2 Since January 2006, have there been any *opportunities* in your country to improve the:

- Availability of essential medications
- Accessibility of essential medications

- Affordability of essential medications

4.3 Since January 2006, have there been any *barriers* in your country to the:

- Availability of essential medications
- Accessibility of essential medications
- Affordability of essential medications

4.4 Since January 2006, have there been any initiatives in your country to change regulations that may restrict physician or patient access to pain relief? (for example, certification required for stocking, prescribing or dispensing opioids)

4.5 Since January 2006, have there been any initiatives in your country to promote attitudinal change in relation to 'opiophobia'?

4.6 Since January 2006, have there been any initiatives in your country that examines access to opioid medication for economically disadvantaged persons?

4.7 Since January 2006, have there been any initiatives undertaken in your country that consider access to essential medication for pain and symptom management as a legal and human right?

5. EDUCATION AND TRAINING INITIATIVES

5.1 Have there been any developments in palliative care training or education initiatives in your country since January 2006?

5.2 Since 2006, in what ways has the *under-graduate* system of hospice and palliative care education developed in your country in relation to:

- Medicine
- Nursing
- Social work
- Other professions

5.3 Since 2006, in what ways has the *post-graduate* system of hospice and palliative care education developed in your country in relation to:

- Medicine
- Nursing
- Social work
- Other professions

5.4 Have any palliative care documents or other materials been translated in your country since January 2006?

5.5 Have there been any initiatives to develop healthcare professional leadership in hospice and palliative care in your country since January 2006? (For example, faculty development or fellowship programmes)

6. SOCIO-CULTURAL, ETHICAL AND MORAL ISSUES

6.1 Has there been any change in public awareness or perception of hospice and palliative care in your country since January 2006?

6.2 Has there been any major public discussion, debate or controversy about hospice and palliative care in your country since January 2006?

6.3 Have there been any initiatives that seek to broaden awareness and understanding of hospice and palliative care in your country since January 2006? (for example, media initiatives)

6.4 Have there been any hospice or palliative care 'success' stories in your country since January 2006? Please describe/provide details.

6.5 At the present time, are there any initiatives in your country that are seeking the legalisation of euthanasia or assisted dying? (Please describe briefly and refer to any official documents or publications since January 2006, if possible)

7. QUESTIONS ON THE FUTURE OF PALLIATIVE CARE DEVELOPMENT

7.1 Please give your view on the future of hospice and palliative care development in your country

7.2 What are the most significant issues facing hospice and palliative care in your country in the next three years? What role do you envisage your association or organisation will play in addressing these issues?

7.3 Given the current economic crisis, what do you anticipate to be the challenges ahead and their implications for palliative care in your country?

Thank you for taking the time to participate in this survey

Annex 3

FACTS QUESTIONNAIRE

A second survey collected 'factual' data on palliative care service provision in each European country; this quantitative survey is known as the 'Facts Questionnaire' and was addressed to a previously identified 'key person' – an 'expert' with extensive knowledge of the 'reality' of palliative care in their location.



European Association for Palliative Care Onlus (EAPC) EAPC FACTS QUESTIONNAIRE FOR THE DEVELOPMENT OF PALLIATIVE CARE IN EUROPE

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Source & goals

Current issues in the development of hospice and palliative care in Europe

Dear Colleague,

The *European Association for Palliative Care (EAPC) Task Force on the Development of Palliative Care in Europe* is to produce a Second Edition of the *EAPC Atlas of Palliative Care in Europe*, which will provide a reliable and comprehensive analysis on the development of the discipline within each European country, and generate an 'evidence base' of clear and accessible research-based information concerning current provision across the region. As a valued contributor to the development of palliative care in Europe, the Task Force would like to take this opportunity to invite you to collaborate with us on this new project. The Task Force has refined and improved the format of the original *Facts Questionnaire* and we would be extremely grateful if you could complete this newly updated version. Many thanks in advance for your help with this matter.

Professor Carlos Centeno, Chair, EAPC Task Force on the development of palliative care in Europe



Carlos Centeno

countries surveyed

53 European countries surveyed

We are seeking information from health practitioners involved in the provision of palliative care across a total of 53 European countries:
Thank you for agreeing to take part in this survey.



- | | | | |
|-----------------------|----------------|---------------------------|--------------------|
| 1. Albania | 16. France | 31. Monaco | 46. Sweden |
| 2. Andorra | 17. Georgia | 32. Montenegro | 47. Switzerland |
| 3. Armenia | 18. Germany | 33. Netherlands | 48. Tajikistan |
| 4. Austria | 19. Greece | 34. Norway | 49. Turkey |
| 5. Azerbaijan | 20. Hungary | 35. Poland | 50. Turkmenistan |
| 6. Belarus | 21. Iceland | 36. Portugal | 51. Ukraine |
| 7. Belgium | 22. Ireland | 37. Republic of Moldova | 52. United Kingdom |
| 8. Bosnia Herzegovina | 23. Israel | 38. Republic of Macedonia | 53. Uzbekistan |
| 9. Bulgaria | 24. Italy | 39. Romania | |
| 10. Croatia | 25. Kazakhstan | 40. Russian Federation | |
| 11. Cyprus | 26. Kyrgyzstan | 41. San Marino | |
| 12. Czech Republic | 27. Latvia | 42. Serbia | |
| 13. Denmark | 28. Lithuania | 43. Slovakia | |
| 14. Estonia | 29. Luxembourg | 44. Slovenia | |
| 15. Finland | 30. Malta | 45. Spain | |



Key points

Current issues in the development of hospice and palliative care in Europe

- The following questionnaire aims to explore the current state of development in palliative care in each European country.
- The questionnaire refers to specific data on the availability of resources and distribution of palliative care services at a national level. Before answering the questions, we recommend that you refer to the EAPC White Paper on standards and norms for hospice and palliative care in Europe*, for clarification of the terminology used within this questionnaire
- Please answer all the questions as accurately as possible. Make use of the space for comments to clarify your information and to describe distinct characteristics of services/health organizations in your country wherever you consider it appropriate to do so. Refer to authors, full references and sources of information since January 2006 whenever possible.
- The Task Force appreciate the level of complexity in completing the Facts Questionnaire but would like to stress that this request is made only once every five years. Please take your time in completing the questionnaire

Key points

- and if you have any queries relating to completion or any other matters relating to the survey, please do not hesitate to contact the EAPC Task Force Research Associate, Dr. Thomas Lynch:
t.lynch@lancaster.ac.uk
- If you wish to contact the European Association for Palliative Care for further information on the background to this project, please do not hesitate to contact Dr. Amelia Giordano at the EAPC Head Office:
Amelia.Giordano@istitutotumori.mi.it

Section 1: Background information
EAPC FACTS QUESTIONNAIRE FOR THE DEVELOPMENT
OF PALLIATIVE CARE IN EUROPE



A. Background information

1.1 What is your full name?

Xavier La Torre, médico internista y coordinador de cuidados paliativos del hospital

1.2 What is the name of the main palliative care institution at which you are based?

English language:

Own language:

1.3 What is your position in the main palliative care institution at which you are based?

1.4 How long have you been employed in this position?

1.5 What are your contact details?

Address:

Telephone/fax: Tel. 00 376 871000, Extensión 3256

Email: xlatorre@saas.ad

Conceptual framework

EAPC FACTS QUESTIONNAIRE FOR THE DEVELOPMENT
OF PALLIATIVE CARE IN EUROPE

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NOTE: The table below shows the conceptual framework that will be used in the *EAPC Atlas of Palliative Care in Europe* and is **for reference only (please do not complete)**. The table is based on different modes of provision of palliative care, classified by place of attendance and level of intervention. In the present study, only data is required that relates to specialist palliative care services (not the basic level of care provided by palliative care professionals working in traditional health care settings). Before completing the Facts Questionnaire, please spend some time studying this framework. We acknowledge that definitions differ between countries and areas and appreciate that in some circumstances the information that you have may not be easily incorporated within this framework; however, we do request that you attempt to adapt your data to conform to the categories shown below.

| Location where palliative care is provided | Resources and services providing general level of palliative care | | Specialized palliative care services | | | |
|---|--|--|---|--|--|--|
| | Basic level of palliative care | | Specialized palliative care services or supportive palliative care services | | Other specialized palliative care services | |
| Patient care in acute hospitals | General Hospital | | Volunteer hospice team (1) | Hospital palliative care support team (2) | Mixed palliative care support team (4) | Palliative care units in tertiary hospitals (Acute, university or general hospitals) (5) |
| Patient care (medium and long term) in places other than general hospital | Nursing homes and other residential facilities | | | | | Palliative care units in non-tertiary hospitals (6) |
| Patient care provided at home | Assistance is provided by general or family physician and nurses in primary care teams | | | Home care support team (3) (the family physician has primary responsibility for the patient) | | Inpatient hospice (7) |
| | | | | | | Day hospice or day-care centre for palliative care (8) |
| | | | | | | Home palliative care team (the palliative care team have primary responsibility for the patient) (3) |

The definitions used in this conceptual framework are adapted from the *EAPC White Paper on standards and norms for hospice and palliative care in Europe*. The exceptions to this are the definitions for *Mixed palliative care support team* and *Home care support team*; there are no definitions of these terms in the *EAPC White Paper*, therefore the definitions used are ones compiled by the Task Force. The number after each different type of service refers to the order in which they appear in Section Two: *Specialized palliative care services*.

Conceptual framework

EAPC FACTS QUESTIONNAIRE FOR THE DEVELOPMENT
OF PALLIATIVE CARE IN EUROPE



| | |
|---|--|
| 1 | Type of Service: Indicate in the table the number of services, and please make reference to the explanatory comments. Your clarification of service type is essential because it is possible that the classification used may be understood differently in different countries. |
| 2 | Description and main characteristics: description of palliative care services is adapted from the <i>EAPC White Paper on standards and norms for hospice and palliative care in Europe</i> http://www.eapcnet.org/download/forPublications/StandardsWP_EJPC2010.pdf |
| 3 | Service Number: write data or estimates regarding the number of different services or resources. When an organization or department has various services (for example, a day care centre, an inpatient and a hospital support team), these should be counted separately in the appropriate boxes. |
| 4 | Number of beds: this refers to the number of "assigned palliative care beds" in inpatient units, and not the total number of hospital or other institution beds. |

Section 2: Specialized palliative care services

EAPC FACTS QUESTIONNAIRE FOR THE DEVELOPMENT OF PALLIATIVE CARE IN EUROPE



| Ref. | Type of Service (1) | Description (2) | Main characteristics (2) | Adults (3) (4) | | Children (3) (4) | |
|------|------------------------|--|--|--------------------|------------|------------------|------------|
| | | | | Number of services | N° of beds | N° of services | N° of beds |
| 1 | Volunteer hospice team | A volunteer hospice team offers support and befriending to palliative care patients and their families in times of disease, pain, grief and bereavement. The volunteer hospice team is part of a comprehensive support network and collaborates closely with other professional services in palliative care. | The volunteer hospice team comprises of specially trained voluntary hospice workers with at least one professional co-ordinator. | | | | |

Comments and additions to the data shown above

| | |
|--|--|
| What is the source of the data you have listed above? | Studies/publications <input type="checkbox"/> Personal estimates/estimates provided by experts <input type="checkbox"/> |
| Please identify the primary source of information in the table; if a person please identify them by their name; if a national survey please indicate the reference of the literature and how the data was obtained (both where applicable) | Name: Source/reference: |
| Additional Comment | |

IMPORTANT: Your annotations and explanations are essential to this study. Please take the time and space you need. You can make additional notes on the back of the questionnaire if needed.

Section 2: Specialized palliative care services

EAPC FACTS QUESTIONNAIRE FOR THE DEVELOPMENT OF PALLIATIVE CARE IN EUROPE



| Ref. | Type of Service (1) | Description (2) | Main characteristics (2) | Adults (3) (4) | | Children (3) (4) | |
|------|---------------------------------------|--|--|--------------------|------------|------------------|------------|
| | | | | Number of services | N° of beds | N° of services | N° of beds |
| 2 | Hospital palliative care support team | <p>Hospital palliative care support teams provide specialist palliative care advice and support to other clinical staff, patients and their families and carers in the hospital environment. They offer formal and informal education, and liaise with other services in and out of the hospital. Hospital palliative care support teams, in the first instance, offer support to healthcare professionals in hospital units and polyclinics not specialised in palliative care.</p> <p>This concept may be applied to residential homes and the hospital-based home care support team</p> | A hospital palliative care support team is composed of a multi-professional team with at least one physician and one nurse with specialist palliative care training. | | | | |

Comments and additions to the data shown above

| | |
|--|--|
| What is the source of the data you have listed above? | Studies/publications <input type="checkbox"/> Personal estimates/estimates provided by experts <input type="checkbox"/> |
| Please identify the primary source of information in the table; if a person please identify them by their name; if a national survey please indicate the reference of the literature and how the data was obtained (both where applicable) | Name: |
| | Source/reference: |
| Additional Comment | |

IMPORTANT: Your annotations and explanations are essential to this study. Please take the time and space you need. You can make additional notes on the back of the questionnaire if needed.

Section 2: Specialized palliative care services
EAPC FACTS QUESTIONNAIRE FOR THE DEVELOPMENT
OF PALLIATIVE CARE IN EUROPE

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| Ref. | Type of Service (1) | Description (2) | Main characteristics (2) | Adults (3) (4) | | Children (3) (4) | |
|------|---|--|--|--------------------|------------|------------------|------------|
| | | | | Number of services | N° of beds | N° of services | N° of beds |
| 3 | Home palliative care team or home care support team | Home palliative care teams provide specialised palliative care to patients who need it at home and support to their families and carers at the patient's home. They also provide specialist advice to general practitioners, family doctors and nurses caring for the patient at home. | The core team of a home palliative care team consists of four to five full-time professionals and comprises of physicians and nurses with specialist training, a social worker and administrative staff. | | X | | X |

Comments and additions to the data shown above

| | |
|--|--|
| What is the source of the data you have listed above? | Studies/publications <input type="checkbox"/> Personal estimates/estimates provided by experts <input type="checkbox"/> |
| Please identify the primary source of information in the table; if a person please identify them by their name; if a national survey please indicate the reference of the literature and how the data was obtained (both where applicable) | Name: |
| | Source/reference: |
| Additional Comment | |

IMPORTANT: Your annotations and explanations are essential to this study. Please take the time and space you need. You can make additional notes on the back of the questionnaire if needed.

Section 2: Specialized palliative care services

EAPC FACTS QUESTIONNAIRE FOR THE DEVELOPMENT
OF PALLIATIVE CARE IN EUROPE



| Ref. | Type of Service (1) | Description (2) | Main characteristics (2) | Adults (3) (4) | | Children (3) (4) | |
|------|--|--|--|--------------------|------------|------------------|------------|
| | | | | Number of services | N° of beds | N° of services | N° of beds |
| 4 | Mixed palliative care support team (Provides palliative care to patients both in the hospital and at home) | Mixed palliative care support team (Provides palliative care to patients both in the hospital and at home) | A mixed palliative care support team is composed of a multi-professional team with at least one physician and one nurse with specialist palliative care training | | | | |

Comments and additions to the data shown above

| | |
|--|--|
| What is the source of the data you have listed above? | <input type="checkbox"/> Studies/publications <input type="checkbox"/> Personal estimates/estimates provided by experts |
| Please identify the primary source of information in the table; if a person please identify them by their name; if a national survey please indicate the reference of the literature and how the data was obtained (both where applicable) | Name: Source/reference: |
| Additional Comment | |

IMPORTANT: Your annotations and explanations are essential to this study. Please take the time and space you need. You can make additional notes on the back of the questionnaire if needed.

Section 2: Specialized palliative care services

EAPC FACTS QUESTIONNAIRE FOR THE DEVELOPMENT
OF PALLIATIVE CARE IN EUROPE

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| Ref. | Type of Service (1) | Description (2) | Main characteristics (2) | Adults (3) (4) | | Children (3) (4) | |
|------|--|--|--|--------------------|------------|------------------|------------|
| | | | | Number of services | N° of beds | N° of services | N° of beds |
| 5 | Palliative care units in tertiary hospitals (Acute, university or general hospitals) (Usually for the short-term treatment of patients with acute and/or complex symptoms) | Palliative care units provide specialist inpatient care. A palliative care unit is a department specialised in the treatment and care of palliative care patients. In some countries, palliative care units will be regular units of hospitals, providing crisis intervention for patients with complex symptoms and problems. | Palliative care units require a highly qualified, multidisciplinary team. Staff members in palliative care units are supposed to have specialist training. The core team consists of doctors and nurses. The extended team comprises of relevant associated professionals, such as psychologists, physiotherapists, social workers or chaplains. | | | | |

Comments and additions to the data shown above

| | |
|--|--|
| What is the source of the data you have listed above? | <input type="checkbox"/> Studies/publications <input type="checkbox"/> Personal estimates/estimates provided by experts |
| Please identify the primary source of information in the table: if a person please identify them by their name; if a national survey please indicate the reference of the literature and how the data was obtained (both where applicable) | Name: |
| | Source/reference: |
| Additional Comment | |

IMPORTANT: Your annotations and explanations are essential to this study. Please take the time and space you need. You can make additional notes on the back of the questionnaire if needed.

Section 2: Specialized palliative care services

EAPC FACTS QUESTIONNAIRE FOR THE DEVELOPMENT OF PALLIATIVE CARE IN EUROPE



| Ref. | Type of Service (1) | Description (2) | Main characteristics (2) | Adults (3) (4) | | Children (3) (4) | |
|------|--|---|--|--------------------|------------|------------------|------------|
| | | | | Number of services | N° of beds | N° of services | N° of beds |
| 6 | Palliative care units in non-tertiary hospitals (Usually for the medium-term treatment of patients with less complex symptoms) | In some countries, palliative care units can be freestanding institutions, providing end-of-life care for patients where home care is no longer possible. The aim of these palliative care units is to offer patient and carers social support in a way that allows for discharge or transfer to another care setting. These units may also provide support for appropriate patients cared for in care homes. | Palliative care units require a highly qualified, multidisciplinary team. Staff members in palliative care units are supposed to have specialist training. The core team consists of doctors and nurses. The extended team comprises of relevant associated professionals, such as psychologists, physiotherapists, social workers or chaplains. | | | | |

Comments and additions to the data shown above

| | |
|--|--|
| What is the source of the data you have listed above? | <input type="checkbox"/> Studies/publications <input type="checkbox"/> Personal estimates/estimates provided by experts |
| Please identify the primary source of information in the table; if a person please identify them by their name; if a national survey please indicate the reference of the literature and how the data was obtained (both where applicable) | Name: |
| | Source/reference: |
| Additional Comment | |

IMPORTANT: Your annotations and explanations are essential to this study. Please take the time and space you need. You can make additional notes on the back of the questionnaire if needed.



| Ref. | Type of Service (1) | Description (2) | Main characteristics (2) | Adults (3) (4) | | Children (3) (4) | |
|------|--|--|--|--------------------|------------|------------------|------------|
| | | | | Number of services | N° of beds | N° of services | N° of beds |
| 7 | Inpatient hospice (Usually a free-standing facility providing palliative care to patients in the last phase of life) | An inpatient hospice admits patients in their last phase of life, when treatment in a hospital is not necessary and care at home or in a nursing home is not possible. | An inpatient hospice requires a multi-professional team that cares for patients and their relatives using a holistic approach. Nursing staff should encompass at least one, preferably 1.2 nurses per bed. A physician trained in palliative care should be available 24 hours a day. There should be dedicated input from psychosocial and spiritual care workers as well as voluntary workers. | | | | |

Comments and additions to the data shown above

| | |
|--|--|
| What is the source of the data you have listed above? | <input type="checkbox"/> Studies/publications <input type="checkbox"/> Personal estimates/estimates provided by experts |
| Please identify the primary source of information in the table; if a person please identify them by their name; if a national survey please indicate the reference of the literature and how the data was obtained (both where applicable) | Name: |
| | Source/reference: |
| Additional Comment | |

IMPORTANT: Your annotations and explanations are essential to this study. Please take the time and space you need. You can make additional notes on the back of the questionnaire if needed.

Section 2: Specialized palliative care services
EAPC FACTS QUESTIONNAIRE FOR THE DEVELOPMENT
OF PALLIATIVE CARE IN EUROPE



| Ref. | Type of Service (1) | Description (2) | Main characteristics (2) | Adults (3) (4) | | Children (3) (4) | |
|------|--|--|--|--------------------|------------|------------------|------------|
| | | | | Number of services | N° of beds | N° of services | N° of beds |
| 8 | Day hospice or day care centre for palliative care | Day hospices or day-care centres for palliative care are spaces in hospitals, hospices, PCUs or the community especially designed to promote recreational and therapeutic activities among palliative care patients. | A day hospice or day-care centre for palliative care is staffed by a multi-professional team supplemented by voluntary workers. It is recommended that there are two nurses present during opening hours, with at least one specialist palliative care nurse for every seven daily attendees. A qualified physician should be directly accessible in case of need. Ready access to other professionals, such as physiotherapists, social workers or spiritual care workers, should be obtained. | | X | | X |

Comments and additions to the data shown above

| | |
|--|--|
| What is the source of the data you have listed above? | <input type="checkbox"/> Studies/publications <input type="checkbox"/> Personal estimates/estimates provided by experts |
| Please identify the primary source of information in the table: if a person please identify them by their name; if a national survey please indicate the reference of the literature and how the data was obtained (both where applicable) | Name: Source/reference: |
| Additional Comment | |

IMPORTANT: Your annotations and explanations are essential to this study. Please take the time and space you need. You can make additional notes on the back of the questionnaire if needed.



A. Officially recognized medical certification

a. Does your country currently provide specialist accreditation to palliative medicine?

| | | | |
|---|--|--|--|
| Yes <input type="checkbox"/> | | Describe the number of years or hours devoted to training as a specialist | |
| Official name/title of Specialty (English) <input type="checkbox"/> | | Describe the structure of clinical education and training | |
| | | What authority or institution certifies the accreditation process? | |
| Official name/title of Specialty (Own language) <input type="checkbox"/> | | Please name the year in which accreditation was officially recognised | |
| | | Please estimate the number of people who have completed the process and have achieved accreditation in your country | |
| Sub-Specialty/ Super-Specialty (An initial form of specialization is required) <input type="checkbox"/> | | Which initial forms of specialization are recognised? (e.g. oncology, family medicine, geriatrics, internal medicine, neurology, etc.) | |
| | | Describe the Sub-Specialty/ Super-Specialty and explain the structure of clinical education and training | |
| | | Please name the year in which accreditation was officially recognised | |
| | | Please estimate the number of people who have completed the process and have achieved accreditation in your country | |
| Other national training awards in Palliative Medicine other than Specialty or Sub-Specialty/ Super-Specialty <input type="checkbox"/> | | Describe any other qualification that recognizes professional status or authorizes someone to work in palliative care (for example, where a person can prove to have sufficient professional experience in the discipline) | |
| | | Please name the year in which accreditation was officially recognised | |
| | | Please estimate the number of people who have completed the process and have achieved accreditation in your country | |

Section 3: Palliative medicine education and training

EAPC FACTS QUESTIONNAIRE FOR THE DEVELOPMENT
OF PALLIATIVE CARE IN EUROPE



a. Does your country currently provide specialist accreditation to palliative medicine?

| | | |
|--|---|--|
| <input type="checkbox"/> In Process | If your country does currently not have accreditation for physicians in palliative care but work has started in this area and there is an ongoing process of accreditation, please provide details of this process and an estimated date by which such accreditation will be achieved | |
| <input type="checkbox"/> Other forms of accreditation | Please describe any other forms of accreditation in your country; for example, postgraduate courses in home-based palliative care. Please provide details of whether any clinical training is included in this process and if so, the duration of such training | |
| There is no official accreditation process in place to certify physicians in palliative care in my country at the present time <input checked="" type="checkbox"/> | | |



b. Questions on undergraduate education in Universities and Medical Schools

| No. | Question | Exact number | Estimation | Comments (please indicate your source of information, for example, national survey, personal experience, etc.) |
|-----|--|---------------------|------------|--|
| 1 | How many medical schools are there in your country? | | | |
| 2 | Can you provide details of the number of medical schools who have spent time developing a curriculum of Palliative Medicine? | Mandatory component | | |
| | | Optional component | | |
| | | Other component | | |

Section 3: Palliative medicine education and training
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C. Questions on the capacity of palliative care workforce training in Universities and Medical Schools

| No. | Question | Exact number | Estimation | Comments (please indicate your source of information, for example, national survey, personal experience, etc.) |
|-----|--|--|------------|--|
| 1 | Can you tell us how many teachers of palliative medicine there are in your country at the present time? | a) Full Professor (cathedratric) | | |
| | | b) Assistant Professor (titular) | | |
| | | c) Other category of Professor (e.g. Associate Professor/ Assistant Principal) | | |
| 2 | Can you tell us how many other teachers of palliative medicine there are that are non-medical professionals and provide details about their area of work (vocational training, etc.) | a) Full Professor (cathedratric) | | |
| | | b) Assistant Professor (titular) | | |
| | | c) Other category of Professor (e.g. Associate Professor/ Assistant Principal) | | |

(1) In each country, the names of the various academic categories of teachers may be different. We have arbitrarily adopted a three-type classification. The first and second classes (a) and (b) refer to official senior academic bodies. The third category (c) refers to another category of academic Professor (e.g. part-time). Please place teachers of palliative care in these specific categories, irrespective of the levels of categorization that exist in your country at the present time.

Section 4: The vitality of palliative care

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A. Questions about National Associations of Palliative Care

a. Are there one or more National Associations of Palliative Care in your country at the present time?

| | | |
|--|--|--|
| <input type="checkbox"/> Yes | Name of National Association 1 (in your own language) | |
| | Name of National Association 1 (in English language) | |
| | Year this National Association was formed | |
| | Does this National Association have an internet web page? If yes, please provide details | |
| | Is this National Association representative of the whole country? | |
| | Name of National Association 2 (in your own language) | |
| | Name of National Association 2 (in English language) | |
| | Year this National Association was formed | |
| | Does this National Association have an internet web page? If yes, please provide details | |
| | Is this National Association representative of the whole country? | |
| <input type="checkbox"/> In process | If there is no National Association of Palliative Care in your country at the present time but some progress is being made in this area, please describe the process and the estimated date by which a National Association will be formed | |
| There is no National Association of Palliative Care in my country at the present time <input type="checkbox"/> | | |

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B. Questions about a directory or catalogue of palliative care services

a. Is there an existing directory or catalogue of palliative care services in your country at the present time?

| | | |
|-------------------------------------|---|-------------------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> Printed version | Title: |
| | | Date first edition published: |
| | <input type="checkbox"/> Online version | Date most recent edition published: |
| | | Internet address: |
| | | Date first edition published: |
| <input type="checkbox"/> In process | If there is no directory or catalogue of palliative care services in your country at the present time but some progress is being made in this area, please describe the process and the estimated date by which a directory or catalogue of palliative care services will be produced | Date most recent edition published: |
| | | |
| | There is no directory or catalogue of palliative care services in my country at the present time | <input type="checkbox"/> |

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C. Questions about congresses, scientific meetings or scientific journals in palliative care

a. Does your country periodically host congresses or scientific meetings at the local, regional or national level that are specifically dedicated to palliative care?

Yes ☐

Title:

Frequency:

Average attendance:

There are no congresses or scientific meetings at the local, regional or national level specifically dedicated to palliative care hosted by my country at the present time ☐

Section 4: The vitality of palliative care



b. Are there one or more scientific journals of palliative care published in your country at the present time?

| | |
|---|--|
| <p>Yes <input type="checkbox"/></p> | <p>Title:</p> |
| | <p>Frequency:</p> |
| | <p>Database index (e.g. PUBMED, CINAHL, etc.):</p> |
| <p>There are no scientific journals of palliative care published in my country at the present time <input type="checkbox"/></p> | |



D. Questions about palliative care research capacity

a. Are there any palliative care research centres, groups or institutions with a critical mass of palliative care research in your country at the present time?

Yes ☐

Name:

Contact details:

There are no palliative care research centres, groups or institutions with a critical mass of palliative care research in my country at the present time ☐

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b. Are there any individuals actively engaged in palliative care research in your country at the present time?

Yes ☐

Name:

Contact details:

There are no individuals actively engaged in palliative care research in my country at the present time ☐



E. Questions about palliative care collaboration

a. Are there any hospice/palliative care institutional 'twinning' or partnership initiatives in your country at the present time?

Yes ☐

Name:

Please describe:

There are no hospice/palliative care institutional 'twinning' or partnership initiatives in my country at the present time ☐

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b. Are there any other significant collaborations between hospice/palliative care groups/organisations in your country and those in other countries at the present time?

| | | |
|--------------------------|-----|---|
| <input type="checkbox"/> | Yes | Name: |
| | | Please describe: |
| | | |
| | | <input type="checkbox"/> |
| | | There are no other significant collaborations between hospice/palliative care groups/organisations in my country and those in other countries at the present time |

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F. Questions about palliative care development

a. Are there any groups/organisations that have 'pioneered' the development of palliative care in your country?

Yes ☐

Name:

Please describe:

There are no groups/organisations that have 'pioneered' the development of palliative in my country ☐

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b. Are there any initiatives that promote World Hospice and Palliative Care Day in your country at the present time?

Yes ☐

Name:

Please describe:

There are no initiatives that promote World Hospice and Palliative Care Day in my country at the present time ☐

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c. Please rank the level of palliative care development in your country according to the 6-part typology shown below (for a full description of the typology please refer to Appendix A)

| | |
|--|--------------------------|
| 1) No known hospice-palliative care activity | <input type="checkbox"/> |
| 2) Capacity building activity | <input type="checkbox"/> |
| 3a) Isolated palliative care provision | <input type="checkbox"/> |
| 3b) Generalized palliative care provision | <input type="checkbox"/> |
| 4a) Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision | <input type="checkbox"/> |
| 4b) Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision | <input type="checkbox"/> |

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A. Questions about legislation relating to palliative care in your country

a. Is there any national law governing the provision of palliative care services?

| | | |
|---|--|--------------------------|
| <input type="checkbox"/> Yes | Please describe briefly and, if possible, refer to official documents or publications | |
| <input type="checkbox"/> In process | If your country does not have a law to regulate the provision of palliative care services but work has commenced in this area and there is an ongoing process, please describe this process and provide an estimated date when such a law will be passed | |
| There is no law to regulate the provision of palliative care services in my country at the present time | | <input type="checkbox"/> |

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b. Are there any published national documents relating to standards and norms for the provision of palliative care services in your country at the present time ?

| | | |
|---|---|---------------------------------|
| Yes <input type="checkbox"/> | Printed version <input type="checkbox"/> | Title: |
| | | Date of first and last edition: |
| | Online version <input type="checkbox"/> | Internet address: |
| | | Date of first and last edition: |
| In process <input type="checkbox"/> | <p>If there are no standards or guidelines on the provision of palliative care services in your country at the present time but some progress is being made in this area, please describe the process and the estimated date by which standards or guidelines on the provision of palliative care services will be produced</p> | |
| <p>There are no standards or guidelines on the provision of palliative care services in my country at the present time <input type="checkbox"/></p> | | |

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c. Is there a National Plan or Strategy of Palliative Care in existence in your country at the present time? ¹

| | | |
|---|--|--|
| <p>Yes <input type="checkbox"/></p> | <p>Please describe briefly and, if possible, refer to official documents or publications</p> | |
| <p>In process <input type="checkbox"/></p> | <p>If your country does not have any National Plan or Strategy of Palliative Care in existence at the present time, but work has commenced in this area and there is an ongoing process, please describe this process and provide an estimated date by which such a plan will be implemented</p> | |
| <p>There is no National Plan or Strategy of Palliative Care in existence in my country at the present time <input type="checkbox"/></p> | | |

¹ 'National Plan' or 'Strategy' refers to regulatory and official publications that are applicable to the whole country (these could be in the form of laws or other official documents); these publications will be endorsed by the Health Authority and contain norms and standards for the development of palliative care, regulations relating to the provision of palliative care services, and guidelines for palliative care research

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d. Is there a National Cancer Control Strategy in existence in your country at the present time? If yes, does it contain an explicit reference to palliative care provision?

Yes ☐

Please describe briefly:

No ☐

There is no National Cancer Control Strategy in existence in my country at the present time ☐

There is a National Cancer Control Strategy in existence in my country at the present time but it does not contain an explicit reference to palliative care provision ☐

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e. Is there a National HIV/AIDS Strategy in existence in your country at the present time? If yes, does it contain an explicit reference to palliative care provision?

| | |
|--------------------------|---|
| <input type="checkbox"/> | <p>Yes</p> <p>Please describe briefly:</p> |
| <input type="checkbox"/> | <p>No</p> <p>There is no National HIV/AIDS Strategy in existence in my country at the present time <input type="checkbox"/></p> <p>There is a National HIV/AIDS Strategy in existence in my country at the present time but it does not contain an explicit reference to palliative care provision <input type="checkbox"/></p> |

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f. Is there a National Primary Health Care Strategy in existence in your country at the present time? If yes, does it contain an explicit reference to palliative care provision?

| | |
|---------------------------------|---|
| <input type="checkbox"/> Yes | Please describe briefly: |
| <input type="checkbox"/> No | <div>There is no National Primary Health Care Strategy in existence in my country at the present time <input type="checkbox"/></div> <div>There is a National Primary Health Care Strategy in existence in my country at the present time but it does not contain an explicit reference to palliative care provision <input type="checkbox"/></div> |

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g. Does your government have a designated policy maker for the delivery of palliative care services at the present time?

☐

Yes

Please describe briefly:

☐

No

My government does not have a designated policy maker for the delivery of palliative care services at the present time

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Section 5: Palliative care policy

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h. Does the Department of Health have specific responsibility for the delivery of palliative care services in your country at the present time?

| | | |
|---------------------------------|--|--|
| <input type="checkbox"/> Yes | Please describe briefly: | |
| <input type="checkbox"/> No | The Department of Health does not have specific responsibility for the delivery of palliative care services in my country at the present time. The following governmental (local, regional, national) or other organisational authorities/bodies do have specific responsibility for the delivery of palliative care services: | |

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i. Are there systems of auditing, evaluation or quality assurance that monitor the standard of palliative care provision in your country at the present time?

| | | |
|--------------------------|------------|---|
| <input type="checkbox"/> | <p>Yes</p> | <p>Please describe briefly:</p> |
| <input type="checkbox"/> | <p>No</p> | <p>There are no systems of auditing, evaluation or quality assurance that monitor the standard of palliative care provision in my country at the present time</p> |

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B. Questions about opioid legislation in your country

a. Is there a standard process for the prescription and acquisition of strong opioids in your country at the present time?

| | | | |
|---|---|---------------------------|--|
| Yes <input type="checkbox"/> | Please describe briefly and, if possible, refer to official documents or publications | Prescription ² | |
| | | Acquisition ³ | |
| In process <input type="checkbox"/> | If your country is in the process of changing regulations relating to prescribing and acquiring strong opioids, please briefly describe this process and provide an estimated date when this change in regulations will be achieved | Prescription ¹ | |
| | | Acquisition ² | |
| There is no standard process for acquiring and prescribing strong opioids in my country at the present time | | <input type="checkbox"/> | |

² The prescription process refers to whether an additional prescription should be signed, and who should sign it: for example, general practitioner or specialist in primary care or hospital doctor only

³ The acquisition or procurement process refers to whether strong opioids are only available in the pharmacy, or in the hospital, or if a special visa is required to obtain such opioids

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b. Are there currently one or more published documents providing clinical guidelines on pain management in your country?

| | | |
|--|--|--|
| Yes <input type="checkbox"/> | Printed version <input type="checkbox"/> | |
| | Online version <input type="checkbox"/> | |
| In process <input type="checkbox"/> | If there are no published documents providing clinical guidelines on pain management in your country at the present time but some progress is being made in this area, please describe the process and the estimated date by which published documents providing clinical guidelines on pain management will be produced | |
| There are no published documents providing clinical guidelines on pain management in my country at the present time <input type="checkbox"/> | | |

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C. Questions about funding for palliative care services in your country

a. Do patients have to pay for palliative care services?

| | |
|---|---|
| Palliative care consultation (please describe briefly) | Full payment (amount) <input type="checkbox"/> |
| | Partial payment (amount) <input type="checkbox"/> |
| | No payment <input type="checkbox"/> |
| Hospitalization (please describe briefly) | Full payment (amount) <input type="checkbox"/> |
| | Partial payment (amount) <input type="checkbox"/> |
| | No payment <input type="checkbox"/> |
| Medication (please describe briefly) | Full payment (amount) <input type="checkbox"/> |
| | Partial payment (amount) <input type="checkbox"/> |
| | No payment <input type="checkbox"/> |

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b. Do 'informal payments' play any part in gaining access to palliative care services in your country at the present time?

| | |
|--------------------------|--|
| <input type="checkbox"/> | Please describe briefly: |
| <input type="checkbox"/> | |
| <input type="checkbox"/> | 'Informal payments' do not play any part in gaining access to palliative care services in my country at the present time |

Section 5: Palliative care policy

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c. Is payment for palliative care services 'disease-specific' in your country at the present time?

| | |
|------------------------------|--|
| <input type="checkbox"/> Yes | Please describe briefly: |
| <input type="checkbox"/> No | Payment for palliative care services is not 'disease-specific' in my country at the present time |

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d. Are specific development funds made available for palliative care in your country at the present time?

| | |
|--|--|
| <div><div><input type="checkbox"/></div><div>Yes</div></div> | <div>Please describe briefly:</div> |
| <div><div><input type="checkbox"/></div><div>No</div></div> | <div>Specific development funds are not made available for palliative care in my country at the present time</div> |



Glossary of Terms

- **Palliative care:** Palliative care is the active, total care of the patient whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.
- **Hospice care:** Hospice care is for the whole person, aiming to meet all needs – physical, emotional, social and spiritual. At home, in day care and in the hospice, they care for the person who is facing the end of life and for those who love them. Staff and volunteers work in multi-professional teams to provide care based on individual need and personal choice, striving to offer freedom from pain, dignity, peace and calm.
- **Supportive care:** Supportive care is the prevention and management of the adverse effects of cancer and its treatment. This includes physical and psychosocial symptoms and side-effects across the entire continuum of the cancer experience, including the enhancement of rehabilitation and survivorship.
- **End-of-life care:** End-of-life care may be used synonymously with palliative care or hospice care, with end of life understood as an

Glossary of Terms

extended period of one to two years during which the patient/family and health professionals become aware of the life-limiting nature of their illness.

- **Terminal care:** Terminal care is an older term that has been used for comprehensive care of patients with advanced cancer and restricted life expectancy.
- **Respite care:** Family members or other primary caregivers caring for a palliative care patient at home may suffer from the continuous burden of care. Respite care may offer these patients and their caregivers a planned or unplanned break.
- **Palliative care approach:** The palliative care approach is a way to integrate palliative care methods and procedures in settings not specialised in palliative care. This includes not only pharmacological and non-pharmacological measures for symptom control, but also communication with patient and family as well as with other healthcare professionals, decision-making and goal-setting in accordance with the principles of palliative care.
- **General palliative care:** General palliative care is provided by primary care professionals and specialists treating patients with life-threatening diseases who have good basic palliative care skills and knowledge.

Glossary of Terms

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Glossary of Terms

- **Specialist palliative care:** Specialist palliative care is provided by specialised services for patients with complex problems not adequately covered by other treatment options.
- **Patients:** Palliative care is not restricted to predefined medical diagnoses, but should be available for all patients with life-threatening diseases.
- **Disease stage:** There is no predefined time point in the course of the disease marking the transition from curative to palliative care.
- **Children and adolescents:** Palliative care for children represents a special, albeit closely related field, to adult palliative care. Palliative care for children begins when the illness is diagnosed, and continues regardless of whether or not the child receives treatment directed at the disease. The unit of care is the child and family.
- **Access to services:** Services should be available to all patients, wherever and whenever they require them, without delay.
- **Continuity of care:** Continuity of care throughout the disease trajectory and across the different settings in the healthcare system is a basic requirement of palliative care.
- **Preferred place of care:** Most patients want to be cared for in their

Glossary of Terms

- own homes, if possible until the time of death. In contrast to this, the place of death for most patients is the hospital or nursing home.
- **Locations of care:** Palliative treatment, care and support are provided at home, in nursing homes, in residential homes for the elderly, in hospitals and in hospices, or in other settings if required.
 - **Palliative care networks:** Regional networks integrating a broad spectrum of institutions and services, and effective co-ordination, will improve access to palliative care and increase quality as well as continuity of care.
 - **Staff in specialist palliative care services:** Services that are not specialised in palliative care can use a palliative care approach or deliver basic palliative care, even when this can only be done by one professional category, or even by one individual (for example, a general practitioner working alone), if they have access to support from an interdisciplinary team.
 - **Voluntary work:** Specialist palliative care services should include volunteers or collaborate with volunteer services.
 - **Palliative care unit:** Palliative care units (PCUs) provide specialist inpatient care. A palliative care unit is a department specialised in the treatment and care of palliative care patients. It is usually a ward within, or adjacent to, a hospital, but it can also exist as a stand-alone service. In some countries, palliative care units will be



Glossary of Terms

- regular units of hospitals, providing crisis intervention for patients with complex symptoms and problems; in other countries, PCUs can also be freestanding institutions, providing end-of-life care for patients where home care is no longer possible. The aim of palliative care units is to alleviate disease- and therapy-related discomfort and, if possible, to stabilise the functional status of the patient and offer patient and carers psychological and social support in a way that allows for discharge or transfer to another care setting. PCUs require a highly qualified, multidisciplinary team.² Staff members in palliative care units are supposed to have specialist training. The core team consists of doctors and nurses. The extended team comprises relevant associated professionals, such as psychologists, physiotherapists, social workers or chaplains. PCUs require an extended team of relevant associated professionals, such as psychologists, social workers, spiritual care workers or physiotherapists. These professions should be included in the team or work in close liaison with it. There should be dedicated input from these professionals, or at least ready access to them should be warranted.

- **Inpatient hospice:** An inpatient hospice admits patients in their last phase of life, when treatment in a hospital is not necessary and care at home or in a nursing home is not possible. An inpatient hospice requires a multi-professional team that cares for patients and their relatives using a holistic approach. Nursing staff should encompass at least one, preferably 1-2 nurses per bed. A physician trained in palliative care should be available 24 hours a day. There should be dedicated input from psychosocial and spiritual care workers as well as voluntary workers.

Glossary of Terms

- **Hospital palliative care support team:** Hospital palliative care support teams provide specialist palliative care advice and support to other clinical staff, patients and their families and carers in the hospital environment. They offer formal and informal education, and liaise with other services in and out of the hospital. A hospital palliative care support team is composed of a multi-professional team with at least one physician and one nurse with specialist palliative care training.
- **Home palliative care team:** Home palliative care teams provide specialised palliative care to patients who need it at home and support to their families and carers at the patient's home. They also provide specialist advice to general practitioners, family doctors and nurses caring for the patient at home. The core team of a home palliative care team consists of four to five full-time professionals and comprises physicians and nurses with specialist training, a social worker and administrative staff.
- **'Hospital at home':** The 'hospital at home' provides intensive hospital-like care for the patient at home.
- **Volunteer hospice team:** A volunteer hospice team offers support and befriending to palliative care patients and their families in times of disease, pain, grief and bereavement. The volunteer hospice team is part of a comprehensive support network and collaborates closely with other professional services in palliative care.

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Glossary of Terms

- The volunteer hospice team comprises specially trained voluntary hospice workers with at least one professional co-ordinator.
- **Day hospice:** Day hospices or day-care centres are spaces in hospitals, hospices, PCUs or the community especially designed to promote recreational and therapeutic activities among palliative care patients. A day-care centre is staffed by a multi-professional team supplemented by voluntary workers. It is recommended that there are two nurses present during opening hours, with at least one specialist palliative care nurse for every seven daily attendees. A qualified physician should be directly accessible in case of need. Ready access to other professionals, such as physiotherapists, social workers or spiritual care workers, should be obtained.

Glossary of Terms

- **Palliative outpatient clinic:** Palliative outpatient clinics offer consultation for patients living at home who are able to visit the clinic.
- http://www.eapcnet.org/download/forPublications/StandardsWP_EIPC2010.pdf

Appendix one : Six-part typology ¹

EAPC FACTS QUESTIONNAIRE FOR THE DEVELOPMENT OF PALLIATIVE CARE IN EUROPE



Typology

Group 1 countries:

- 1) No known hospice-palliative care activity. Although we have been unable to identify any hospice-palliative care activity in this group of countries, we acknowledge that there may be instances where, despite our best efforts, current work has been unrecognized.

Group 2 countries:

- 2) Capacity building activity. In this group of countries, there is evidence of wide-ranging initiatives designed to create the organisational, workforce and policy capacity for hospice-palliative care services to develop, though no service has yet been established. The developmental activities include: attendance at, or organisation of, key conferences; personnel undertaking external training in palliative care; lobbying of policy-makers and health ministries; and incipient service development.

Group 3 countries:

- 3a) Isolated palliative care provision. This group of countries is characterized by: the development of palliative care activism that is patchy in scope and not well-supported; sourcing of funding that is often heavily donor-dependent; limited availability of morphine; and a small number of hospice-palliative care services that are often home-based in nature and relative to the size of the population.
- 3b) Generalized palliative care provision. This group of countries is characterized by: the development of palliative care activism in a number of locations with the growth of local support in those areas; multiple sources of funding; the availability of morphine; a number of hospice-palliative care services from a community of providers that are independent of the healthcare system; and

¹ Six-part typology reproduced with kind permission of the Worldwide Palliative Care Alliance

Typology

the provision of some training and education initiatives by the hospice organizations. community of providers that are independent of the healthcare system; and the provision of some training and education initiatives by the hospice organizations.

Group 4 countries:

- 4a) Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision. This group of countries is characterized by: the development of a critical mass of palliative care activism in a number of locations; a variety of palliative care providers and types of services; awareness of palliative care on the part of health professionals and local communities; the availability of morphine and some other strong pain-relieving drugs; limited impact of palliative care upon policy; the provision of a substantial number of training and education initiatives by a range of organizations; and interest in the concept of a national palliative care association.

- 4b) Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision. This group of countries is characterized by: the development of a critical mass of palliative care activism in a wide range of locations; comprehensive provision of all types of palliative care by multiple service providers; broad awareness of palliative care on the part of health professionals, local communities and society in general; unrestricted availability of morphine and all other strong pain-relieving drugs; substantial impact of palliative care upon policy, in particular upon public health policy; the development of recognized education centres; academic links forged with universities; and the existence of a national palliative care association.

