



PhD Thesis

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Palliative Care in the Hospital

A mixed-methods study of the general palliative care in a hospital in Denmark.

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Submitted

4th January 2016

This thesis has been submitted to the Graduate School of The Faculty of Health and Medical Sciences, University of Copenhagen.

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The Cold

*I am looking out the window,
At the snow, the cold.
It is also cold inside,
Here inside me.*

*I am looking at the room,
A hive of activity.
Nurses' hands working,
Thoughts elsewhere.*

*She is lying in bed,
Quiet, unmoving.
She who is about to depart –
I wonder where her thoughts lie?*

*I hear words directed at me,
But they collide with a wall,
A wall of judgement.
Is this really me?*

*I need to escape,
But remain where I am,
Stiffened, bruised.
Are the others aware of me too?*

*I take action when it's all over,
Hold her hand and stroke her hair
I wonder if she felt the cold as well,
The cold that paralysed me.*

(A poem written by the candidate as a part of the observational study in this PhD.)

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Preface and Acknowledgements

This thesis is about general palliative care in a Danish hospital and was conducted and completed when I was enrolled as a PhD student at the Faculty of Health Sciences, University of Copenhagen, in the period from 1st February 2012 to 4th January 2016.

The empirical part of the study took place at a large regional hospital, which, for reasons of anonymity, will not be named.

During the process of this PhD several individuals and institutions have made crucial contributions. My sincere gratitude goes to:

- ❖ My principal supervisor Bibi Hølge-Hazelton for being extremely supportive and understanding throughout the course of my PhD work, while simultaneously remaining professional and knowing how and when to raise her expectations of me. Thank you!
- ❖ My co-supervisor Lene Jarlbæk for sharing her expertise on the quantitative field, and for expanding my understanding of this work.
- ❖ The Novo Nordisk Foundation, Hospital North, Region Zealand, Denmark and the Health Research Foundation in Region Zealand, who all provided funding.
- ❖ The hospital management and head nurses for their faith in this project and for their financial assistance. I am truly grateful, as the work could not have been carried out without this support.
- ❖ Professor Helle Timm and the staff at PAVI for their financial support during the writing of the PhD protocol, for serving as sparring partners, for offering good advice and for their warm and welcoming attitude; and Karen Marie Dalgaard for excellent collaboration on a systematic review.
- ❖ The practice development nurses at the hospital for showing their continuous interest in the study.
- ❖ The departmental managers and nurses for allowing me to study their practice during the observational study, and the patients and relatives who always made me feel welcome.
- ❖ The Regional Research Unit and my supportive colleagues, who were always helpful.

- ❖ The Quality Unit at the hospital, who helped me with data and information concerning the Danish Healthcare Quality Programme – special thanks to Nete Villebroe Munk.
- ❖ Angela Heath-Larsen for her excellent language revision of the papers and this thesis.
- ❖ My fellow PhD students from the national palliative network group (PIP), for their participation and support in establishing this network.
- ❖ All of my colleagues, PhD students and postdoctoral scholars at the hospital who created an inspiring, educational and friendly environment.
- ❖ My Canadian colleagues Rose DeAngelis, Bessy Bitzas and Lisa Chan for allowing me to visit their facilities abroad and for our inspiring conversations.
- ❖ To my current employer, the surgical department at Roskilde and Køge Hospitals for their patience, support and encouragement while I was completing my PhD. A special thanks to Birgitte Østergaard.
- ❖ My family and friends for their continuous love and support. Especially my sister for help with skills I lacked. And a special thought for my father who did not get to see the end of this, but who I know is watching proudly from Heaven.
- ❖ Most importantly of all, my children Caroline and Frederik, who always remind me of what really matters and who bring love, laughter and sunshine into my life.
- ❖ My one and only Marius, whose support cannot be described in words. For his love, understanding and faith in me. None of this could have been achieved without you!

Heidi Bergenholtz, January 2016

The thesis is based on the following papers:

Paper 1:

Organization and evaluation of generalist palliative care in a Danish hospital.

Bergenholtz H, Hølge-Hazelton B, Jarlbaek L.

Published in BMC Palliative Care May 2015 14, (1) 23

Paper 2:

The Culture of General Palliative Nursing Care in Medical Departments - An Ethnographic Study.

Bergenholtz H, Jarlbaek L, Hølge-Hazelton B.

Published in the International Journal of Palliative Nursing April 2015. 2;21(4):193-201

Paper 3:

Generalist palliative care in hospital – cultural and organisational interactions. Results of a mixed-methods study.

Bergenholtz H, Jarlbaek L, Hølge-Hazelton B.

E-published ahead of print in Palliative Medicine December 2015

Outline of the Thesis

This thesis consists of five chapters and three published papers. The outline is following:

Chapter 1 is an introduction and describes the background, the concepts used in this thesis and the aims of the study.

Chapter 2 describes the method, design and material for the study. This chapter will describe the individual quantitative-, qualitative- and mixed-methods phases, along with the relevant theoretical inspiration used in the phases. Ethical considerations will also be presented.

Chapter 3 presents the results and findings from the three studies.

Chapter 4 is a discussion on the principal results and findings as well as methodological considerations in the three phases. The results and findings will be discussed in the light of existing research in order to suggest workable solutions for general palliative care in the hospital.

Chapter 5 will conclude on the study and give perspectives for further research in general palliative care in the hospital.

The three papers are subsequently attached with separate lists of references.

Chapter 1: Introduction and Background

Introduction

This PhD thesis treats the subject of general palliative care in a hospital in Denmark, based on a mixed-methods study.

During the last decade it has been emphasised that palliative care is relevant for all life-threatening diseases – not only cancer (World Health Organization 2013). This shift in a broadened understanding of palliative care to include all patients with life-threatening diseases has made an impact on international policies and recommendations, as well as national and regional strategies and guidelines (National Board of Health 2011; Radbruch and Payne 2010).

Yet newspaper headlines like the following are regularly seen in Denmark: “*The effort for the dying is lagging behind (in hospitals)*” (Gustavsen 2015) and “*Palliative care for patients with life-threatening illnesses is predominantly given to cancer patients. Other patient groups are hardly offered any palliative care*” (Elmhøj and Piil 2014). Since 50% of the Danish population will end their lives in hospital (National Board of Health 2010), the onus is on hospitals to offer and initiate palliative care. But when the public debate describes palliative care in hospitals as alienating, unworthy and selective with regard to cancer patients it appears that the target group of patients has not been reached.

In my clinical work as a registered nurse I personally experienced a profound difference in the options for palliative care available to patients with cancer and patients with other categories of disease. This had such an impact on me, that it became a subject upon which I was determined to shed light.

It is here that this thesis takes its point of departure, with a determination to investigate how palliative care is practised and organised in hospital departments, which do not specialise in this type of care.

Background and Concepts

This section will present a detailed background for concepts used in this thesis.

Definition and Development of the Concept of Palliative Care

In this section the broad concept of palliative care will be presented. Palliative care is a multidisciplinary approach aimed at relieving physical, psychological, social and spiritual symptoms which can arise from the onset of life-threatening diseases (National Board of Health 2011).

Modern palliative care has its roots in the hospice philosophy, which was developed in England in the 1960s. Doctor, nurse and social worker Dame Cicely Saunders (1918-2005) was one of the pioneers in the field and established St Christopher's Hospice in England in 1967. The hospice movement and philosophy was established as a reaction to the excessive use of life-prolonging medical technology which was developing during the 20th century. The hospice movement focused on the quality, rather than length, of life during the course of a disease (Randall and Downie 2006). This philosophy aimed to achieve a better quality of life and better conditions for the dying by providing holistic care for patients and their relatives (Saunders 2001). Research in pain and symptom control was a dominant focus (Clark 2007). The success of St Christopher's Hospice led to hospice development throughout the world. During the 1970s the hospice ideal began to spread into other settings in the UK (ibid.), such as home and hospital care, although still with a focus on symptom management for cancer patients. In the rest of Europe hospice services began during the 1980s. In Denmark, palliative care has been a developing field since the late 1980s (Timm 2014), the first Danish hospice being founded in 1992. Since then the expansion of specialist palliative care units and hospices has grown substantially (Knowledge Centre for Rehabilitation and Palliative Care 2015).

Saunders' concept of "total pain" (Saunders et al. 1995), which involves physical, emotional, social and spiritual distress, is today embedded in WHO's definition of palliative care as a global concept. WHO's 1989 definition of palliative care was revised in 2002, such that it now reads:

"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering

by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”(World Health Organization 2014).

The change in the definition by WHO can be seen as marking the start of the expansion of knowledge on palliative care to include all patients with life-threatening diseases, rather than cancer alone. In a Danish context the Danish National Health Board published their first guidelines for palliative care in 1999. They were revised in 2011 and now also include life-threatening diseases (National Board of Health 2011) as proposed by WHO.

Palliative care is an approach and not a clinical specialty. It is a subject area which covers a number of clinical specialties (National Board of Health 2011). In the UK, palliative medicine was approved as a sub-specialty under general medicine in 1995, but in many countries it is still not considered part of general medicine (Clark 2007).

In Denmark, as in many other countries, palliative care is organised at two levels: 1. General palliative care and 2. Specialised palliative care (Gardiner et al. 2012; National Board of Health 2011; Radbruch and Payne 2010). General palliative care is defined as care provided to those affected by life-threatening diseases as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team. This includes hospitals as well as primary care. Specialist palliative care refers to the care performed by healthcare professionals whose main activity is the provision of palliative care: in hospices, palliative care teams and palliative care units. In Denmark only about 28% of terminal patients are treated at a specialist level and 96% of these patients have cancer (National Board of Health 2011). Therefore most of the effort on palliative care should be provided at the general level, making palliative care a task that almost all healthcare professionals should be able to provide – as explained by Gott et al. (2012).

In national recommendations in Denmark (National Board of Health 2011) palliative care is divided into early, late and terminal phases. The early phase can last for years and often involves a life-prolonging treatment of the underlying disease. The late phase can last for months after specific disease-targeted treatment is ended. The terminal phase lasts for days or weeks and is initiated when death is imminent. A recent paper written by experts in palliative care in Denmark (Jarlbaek et al. 2014) elaborates on these phases and suggests that palliative care should be provided over a longer period of time and should be given alongside treatment of the specific disease since this treatment

also can be described as relief-giving as it alleviates the symptoms related to the underlying disease. Palliative care therefore ought to be provided alongside the treatment of chronic illnesses (Jaarsma et al. 2009).

The concept of palliative care derives from the notion of achieving a “good death” (Randall and Downie 2006). The aim of achieving a good death has its roots in a religious notion and strives towards “...an acceptance of human mortality and a recognition that human weakness and sin could be forgiven...” (Randall and Downie 2006 p. 5). In a Danish context Karen-Marie Dalgaard (2010) describes the good death as an ideal for palliative care, but claims that it is a matter of personal experience; therefore, she says, it is a prerequisite that the healthcare professional should determine whether the dying patient perceives their own experience as a good death. Dalgaard argues that the ideal of a good death cannot always be attained: sometimes it will not be a possibility because of societal structures and a lack of control over the course of an illness.

Jacobsen (2010) describes how a growing interest in the good death is an expression of a more personalised and intimate relationship with death, whereby there is a desire to accept the process of death as a part of life, rather than denying it. In the field of palliative care this creates an increased focus on individual autonomy and the involvement of patients and relatives in decisions, which in the past were taken by the doctor alone (ibid.). Since the concept of a good death is influenced by societal structures, such as culture, religion and economy, as well as being personalized, it is impossible to reach a universal consensus on what the good death should consist of.

The terms ‘palliative care’, ‘end-of-life care’, ‘hospice care’ and ‘terminal care’ are often used interchangeably for the same topic in the literature. There is a variety of terms in use among different countries around the world. The European guidelines (Radbruch and Payne 2010) use the terms ‘palliative care’, ‘end-of-life care’ and ‘hospice care’ synonymously and refer to the care given to the patient with a life-threatening and life-limiting disease. The term ‘terminal care’ is used to describe the care given in the last days/hours of life (ibid.). In this thesis palliative care is used as a general term, covering the early, late and terminal phases in a life-threatening illness trajectory.

Despite the development and expansion of the concept of palliative care, the understanding and practice of this type of care may not have followed. A recent qualitative study by Weil et al. (2015) performed in an acute care setting has shown that healthcare professionals have contradictory

understandings of the term. The term is primarily used as end-of-life care for cancer patients. This is found to be problematic, since the full extent of palliative care cannot be provided when it is understood to be relevant only to the very end of life. This may indicate that the understanding is contradictory, but it remains unknown whether the development of the concept has reached all organisational levels in the hospital setting, and whether it has expanded to become more than something offered only to cancer patients at the very end of life.

Since it has been emphasised that palliative care is relevant for all life-threatening diseases, it is suggested that it should be a priority across the healthcare sector and must be established through an overall policy to ensure its structure and financing at all levels (Gomez-Batiste et al. 2013; World Health Organization 2013). Clark et al. showed in 2002 that there are variations in the care, due to management patterns, work organisation and the use of resources in the hospital, but there is only very limited knowledge about how and whether the organisation of palliative care in the hospital today, is controlled by the overall policy.

Integrated Palliative Care

Integrated care is a concept that has received growing international attention in response to a lack of coordinated care. It focuses on organisation, coordination and integration of care provision, as described by Kodner and Spreeuwenberg in 2002.

In palliative care attention has been paid to the development of models for integrated care and integrated care pathways. Frameworks and pathways have been developed in order to systematise and evaluate the actual care given (Bainbridge et al. 2010). Two well-known approaches are The Liverpool Care Pathway and The Golden Standard Framework, which also both have been subject to implementation barriers (Department of Health (UK) 2013; Di et al. 2015; Shaw et al. 2010).

In national (National Board of Health 2011) and European guidelines (Radbruch and Payne 2010) it is recommended that palliative care be delivered concurrently with treatment, as also reflected in the “integrated trajectory model” described by Lynn and Adamsson in 2003 (p. 7). This model has been developed such that it is now diagnosis-independent, which is why palliative care for non-cancer patients can be included in the model.

In the “integrated trajectory model”, it is recommended that both treatment and palliative care can be integrated. In this sense, rehabilitation should also be mentioned. Since palliative care and rehabilitation share common goals (Santiago-Palma and Payne 2001), it makes sense to combine these, especially for patients with chronic illnesses, which can last for many years.

A new report by Silver et al. (2015) claims that both palliative care and cancer rehabilitation have complementary components of care, such as improving and restoring quality of life. At the same time there is a difference, because palliative care addresses immediate needs whereas rehabilitation often operates over a longer time frame.

In a neurological setting (non-cancer) Turner-Stokes et al. (2007) have found an overlap between neurology, rehabilitation and palliative medicine. They highlight the importance of collaboration between different specialties. According to Javier and Montagnini (2011), rehabilitation interventions have a positive effect on functional status, quality of life and relief of pain and anxiety in hospice and palliative care patients. It is therefore important to integrate both rehabilitation and palliative care into an illness trajectory in order to achieve better symptom relief. However, it is not known whether this integration is a part of the daily practice in the hospital when caring for patients with life-threatening diseases.

In order to integrate treatment, rehabilitation and palliative care into one, it is recommended that palliative care should be initiated at an early stage. The initiation of early palliative care has been shown in several studies to benefit many patients as it alleviates symptoms, allows planning of the palliative care and helps to reduce the number of unexpected admissions and deaths (Bauman and Temel 2014; Dalgaard et al. 2010; Reyes-Ortiz et al. 2014; Temel et al. 2010; Thoonsen et al. 2011). However, several challenges arise with respect to early initiation, relating to the lack of consensus on the initiation of palliative care (Murray et al. 2005), the unpredictability of the trajectory (Fischer et al. 2006; Murtagh et al. 2004) and communication on this topic (Dalgaard et al. 2010; Murray et al. 2005). A lack of consistency regarding the late implementation of end-of-life management plans has been demonstrated in a Danish haematological setting by Dalgaard et al. (2010). Dalgaard also demonstrated in a recent Danish systematic review (Dalgaard et al. 2014) that this delay may be caused by a lack of validated methods for early identification of palliative care needs in clinical practice, especially for non-cancer (COPD and chronic heart failure) patients.

Dying in Hospital

Dying in hospital has been a research topic for decades. This research started in America, where Glaser and Strauss in the 1960s described how nurses organised their work around different trajectories of dying and how different types of awareness of dying were shared or not shared by the patients and staff in hospitals (Glaser and Strauss 1965; Glaser and Strauss 1968). At the same time the American sociologist David Sudnow found that health-care professionals based their management of dying patients in the hospital on characteristics such as age and character (Sudnow 1967). This meant that management of dying was often seen as successful with regard to elderly patients for whom death had been anticipated, whereas the death of a child or middle-aged patient was more difficult for nurses to cope with. These studies showed that sometimes: *"...the work pattern is, at least in some respect, out of step with the dying process"* (Glaser and Strauss 1968 p.1). Another American influence in the development of palliative care in the hospital is the work of psychiatrist Elisabeth Kübler-Ross, who encouraged the acknowledgement of dying as a part of life rather than a medical failure (Kübler-Ross 1969).

In 1995, the SUPPORT study (The SUPPORT Principal Investigators 1995) of 10,000 seriously ill patients in five American teaching hospitals found that many patients suffered prior to death mainly due to pain and a lack of patient-physician communication. Since then many studies have investigated palliative care but there still appear to be challenges to overcome in the provision of caring for the dying in hospital. This has been reflected in new research, which has shown that the hospital is the most undesirable setting for the place of death in a Czech population (Loucka et al. 2014). In a Danish setting, Neergaard et al. (2011) finds that the preferred place of death is at home.

Providing palliative care in hospital has been related to numerous challenges. Both older and more recent international studies, in an oncological context as well as other categories of illness in acute care settings, have described these challenges, which arise for a number of reasons, including:

- ❖ The primary emphasis in hospital is on life-prolonging treatment (Dahlborg-Lyckhage and Liden 2010; Gardiner et al. 2011; Willard and Luker 2006)
- ❖ Lack of resources and time (Gardiner et al. 2011; Sigurdardottir and Haugen 2008; Thompson et al. 2006a; Wotton et al. 2005)

- ❖ Lack of knowledge and skills (Gill and Duffy 2010;Mohan et al. 2005)
- ❖ Lack of communication and teamwork around the palliative care patients (Hamilton and McDowell 2004;Wallerstedt and Andershed 2007)
- ❖ Lack of privacy and too much noise in the departments (Hawker et al. 2006;Payne et al. 2007)
- ❖ Personal factors in health-care professionals, such as a lack of emotional engagement (Costello 2001); the quality of dying seems to be strongly related to the medical care and staff attentiveness (Witkamp et al. 2015)
- ❖ The transition to palliative care is unstructured (Gott et al. 2011) and is often postponed (Dalgaard et al. 2010)
- ❖ Lack of access to palliative care resources (Fink et al. 2013; Hess et al. 2014) and barriers in referral to specialist palliative care (Boland et al. 2013; Lunney et al. 2003)
- ❖ Lack of administrative support (Fink et al. 2013), despite a great interest in integrating palliative care in acute settings from an administrative perspective (Grudzen et al. 2013)
- ❖ Lack of preparation by the healthcare professionals in the hospital of the majority of patients and relatives for imminent death (Witkamp et al. 2015).

The hospital setting seems far from an ideal situation for end-of-life care (Parish et al. 2006) and a recent Canadian ethnographic study of palliative care in medical departments suggest that this may be caused by a clash between the curative and the palliative paradigms (Chan 2014).

When defining a good death in a modern hospital DelVecchio Good et al. (2004) find that physicians use the concepts of time and process (whether the death is unexpected, peaceful or prolonged); decisions on medical treatment (whether a gentle death is facilitated); communication with patients (avoiding misunderstandings and conflicts). Often the experiences of "good" and "bad" deaths are based on the extent of the nurses' sense of control in the dying process (Costello 2006). Furthermore, a large study of 861 American nurses working in critical care (Beckstrand et al. 2006) finds that the barriers in providing a good death were related to time constraints, staffing patterns and decisions based on the physicians' rather than the patients' needs.

There is a lack of studies focusing on general palliative care in a Danish context, but a recent PhD study (Sølver 2013) found that some of the challenges for creating continuity for patients with

cancer in a hospital setting are related to the organisational framework and routines. Whether this is a general problem, which also applies to non-cancer patients, remains unknown.

In Denmark, general palliative care is not only addressed by research, but also in the hospitals' national accreditation procedure, the 'Danish Healthcare Quality Programme' – DDKM (a Danish abbreviation for: 'Den Danske Kvalitets Model') (The Danish Institute for Quality and Accreditation in Healthcare (IKAS) 2009) – in the standard 'Palliative care of the incurable patient and the patient's relatives'. DDKM aims to "improve the quality of the patient trajectory" and evaluates this quality through an accreditation procedure. However, it is not known how this procedure affects the quality of palliative care.

The Patient in Need of Palliative Care and Access to Palliative Care Services

Defining the patient in need of palliative care (the palliative care patient) is not an easy task. Following the European and National Danish recommendations (National Board of Health 2011;Radbruch and Payne 2010) the palliative care patient is the patient diagnosed with a life-threatening and/or debilitating disease. It is suggested that awareness is needed for the provision of palliative care for non-cancer patients, such as those with neurological diseases, HIV/AIDS and cardiac, pulmonary or renal diseases.

Research has shown that profound differences exist between cancer and non-cancer diagnoses (Edmonds et al. 2001;Gore et al. 2000;Tanvetyanon and Leighton 2003) and in the illness trajectories which make the patients' needs different (Murray et al. 2005;Murtagh et al. 2004). In 2010 the British Medical Journal published a spotlight issue to address dying and palliative care as a matter for all people (Delamothe et al. 2010). This spotlight issue contained review articles written by British and Scottish experts and focused on the identification of patients in need of palliative care by using clinical indicators (Boyd and Murray 2010); the raising of awareness on talking about dying matters (Seymour et al. 2010) and how to ensure a good death for all (Ellershaw et al. 2010). This spotlight issue was an acknowledgement of the care needed for all patients. It offered suggestions which healthcare professionals could integrate in their daily lives and referred to several studies which covered the very end of life (the final days or hours). The spotlight issue called for further research on the assessment of accurate and timely diagnosis in dying as well as raising public awareness of dying to ensure that death could always be well-managed.

Profound challenges in identifying the patients in need of palliative care have been described. Two recent systematic reviews have addressed the difficulties of defining a palliative care population in randomised controlled studies. Sigurdardottir et al. (2014) included 336 studies in their review and found great variations in how these populations were described. However, the variables age, gender, cancer diagnosis, performance status and survival were most commonly used. Van et al. (2013) included both cancer and non-cancer patients in their review of 60 RCT studies and also found a lack of clarity in the definitions. It should be noted that half of the studies for non-cancer patients were excluded, since they did not relate to terminal or palliative care, even though the populations had no options for curative treatment. A new Danish study (Benthien et al. 2015) has come close to a definition for cancer patients, but the classification of the non-cancer patients is still ongoing. In this thesis the palliative care patient is defined as a patient with a life-threatening disease (whether cancer or not).

A status report from WHO from July 2015 (World Health Organization (WHO) 2015), based on the Global Atlas (World Palliative Care Alliance and WHO 2014), states that only 14 % of people in need of palliative care actually receive it.

Significant barriers are seen in the development of palliative care in Western Europe (Lynch et al. 2010) and particularly in Denmark (Hoeftler and Vejlggaard 2011; Vittrup and Timm 2013). In Denmark there is, for example, a lack of access to palliative care beds in hospitals and hospices, a lack of doctors trained in palliative care and a lack of good continuity of care at the end of life (Hoeftler and Vejlggaard 2011). A report just released in 2015 by The Economist ranks Denmark as number 19 out of 80 countries when measuring indicators on the palliative and healthcare environment, human resources, affordability of care, quality of care and community engagement (The Economist Intelligence Unit 2015).

During the period 2008 – 2015 the number of specialist palliative care units in Denmark increased from 16 to 55 (Knowledge Centre for Rehabilitation and Palliative Care 2015; Timm et al. 2012) and in this respect a rapid expansion of specialist palliative care is witnessed. However, late referrals to the specialist level is an issue still discussed in an oncological context (Davis et al. 2015). Clinical guidelines for specialised palliative care have also been developed, with the establishment of the Danish Multidisciplinary Cancer Group for Palliative Care (DMCG-Pal) in 2009 (DMCG-Pal 2015).

This development is especially directed towards cancer patients, as there still seems to be a lack of a palliative care tradition for other groups of patients. Habraken et al. (2009) finds that despite having the same symptoms, such as breathlessness and physical and social functioning, the non-cancer patients have a lower quality of life than those with a cancer diagnosis. A recent American study likewise found that patients with heart failure had unresolved symptoms and a higher level of distress compared to patients with cancer (Kavalieratos et al. 2014). However, non-cancer patients are less likely to receive palliative care (Cohen et al. 2012; Rosenwax and McNamara 2006) and differences in the delivery of care may derive from a lack of knowledge and education among healthcare professionals (Ahmed et al. 2004).

These diagnosis-based differences have been shown to create challenges in the provision of palliative care, such as barriers in referral to specialised palliative care (Boland et al. 2013; Lunney et al. 2003) which is still limited for non-cancer patients (Hess et al. 2014). In a study by Clemans et al. (2014) of the prevalence of palliative patients in an acute medical setting it was demonstrated that two thirds of the patients, who were identified as palliative, were patients with non-malignant diseases. Other research conducted in similar settings shows that dying patients have unmet needs, such as breathlessness and pain (Sigurdardottir and Haugen 2008; Teno et al. 2004), and this symptom-control is inadequate for the most severely ill patients (Toscani et al. 2005). However, more than 80% of the patients referred to palliative care teams are patients with cancer (Clemans et al. 2014).

In sum, it is well-documented that cancer patients are more likely to have access to palliative care services than patients with other life-threatening diseases, indicating that the broadened understanding of palliative care to include all patients with life-limiting illnesses, which is reflected in international, European and national policies and recommendations (National Board of Health 2011; Radbruch and Payne 2010; World Health Organization 2014), has not yet reached its target group. However, there is a lack of knowledge on whether this indication corresponds to reality and how recommendations are being implemented and practiced in hospitals.

General Palliative Nursing Care in Hospital

The nursing role in palliative care in a generalist setting does not have a broadly accepted definition. This means that palliative nursing care is not defined as a specific kind of nursing, but often regarded as an integrated part of nursing care in general.

In Oncology the difference between the generalist- and the specialist nurse in palliative care is described as: the generalist nurse has knowledge about caring for patients with chronic illnesses, whereas the specialist nurse has skills in pain and symptom management for patients with multiple serious illnesses (Wienczek and Coyne 2014). However the role of the nurse working outside oncology is missing.

Nursing itself is also a concept which is much debated and can be difficult to grasp. As described by Lugton and McIntyre: *“Nursing is a complex activity, a practice-based, eclectic discipline. Its very essence is concerned with human nature, professional caring and the building of therapeutic relationship, with the practice of nursing involving complex decision-making processes”* (Lugton and McIntyre 2005). Nursing is directed towards four sectors of activity, as described by The Danish Nursing Ethical Guidelines in Denmark (Sygeplejeetisk råd 2014), which are to carry out, disseminate, manage and develop nursing care.

The difference between nursing care and palliative nursing care is their perspective: palliative nursing care is directed towards the care of patients with life-threatening diseases. The Danish Nursing Ethical Guidelines emphasise that a part of the nursing task is to: *“...contribute to a dignified death and to help to ensure that hopeless treatment is ended or avoided altogether”* (Sygeplejeetisk råd 2014).

In this thesis general palliative nursing care is defined as the nursing care given to a patient with a life-threatening disease in hospital.

Even though general palliative nursing is not defined *per se*, exploratory qualitative studies have illuminated the role and skills of the nurses working in palliative care. In a study by Hamilton and McDowell (2004) the role of the nurses working with palliative care in hospital settings was shown to be central and multidimensional, including dimensions of communication, teamwork, holistic care, resources and culture. In medical departments Johnson et al. (2012) described the role of the

nurse as pivotal to ensuring both specialised and generalist palliative care. Since end-of-life care has been described as multifaceted, involving physical, psychological, social, spiritual and existential nursing care (Lindqvist et al. 2012), there is an expectation that the nurses should have multifaceted palliative skills both in pharmacological as well as non-pharmacological relief. Since nurses spend more time at the patient's bedside than physicians, they are expected to have skills and knowledge to meet the needs of the patients and the carers (Malloy et al. 2008).

Studies have also shown that a majority of nurses working within general palliative care see palliative nursing as an integral part of the care provided, but they do not view the hospital as the ideal setting for the dying patient (Ferrand et al. 2008;McDonnell et al. 2002)

The perspectives and experiences of nurses working with palliative care patients in hospital, and the related challenges, have been thoroughly explored (Gardiner et al. 2011; Gill and Duffy 2010, Hamilton and McDowell 2004; Hopkinson et al. 2003; Mohan et al. 2005; Thompson et al. 2006a; Wallerstedt and Andershed 2007) and are intertwined with the many challenges in the hospital described in above section. Nurses have reported difficulties in providing palliative care when nursing care is dominated by a focus on symptom management (Wotton et al.2005) and nurses experience a feeling of being pulled in all directions (Thompson et al. 2006a). Furthermore, nurses report that they have difficulties in recognising palliative care needs, which leads to continuous acute care – even very late in an illness trajectory (Bloomer et al. 2013;Davidson et al. 2002;Wotton et al. 2005). Even though most studies relate to the terminal phase of palliative care, nurses acknowledge that an earlier initiation of palliative care could benefit patients (Boyd et al. 2011) and nurses have also been shown to function as a facilitating link in the transition between the different palliative phases (Thompson et al. 2006b).

Distress and frustration among nurses working with palliative care have been described in qualitative research as relating to a reality that fails to match the nurses' ideal of care, or to a feeling of having contributed to a "bad" death (Hopkinson et al. 2003;Kristjanson et al. 2001;Low and Payne 1996;Wotton et al. 2005). Other moral dilemmas among nurses relate to communication with the patient, regarding how appropriate it is to continue with curative treatment (Georges and Grypdonck 2002).

Johansson and Lindahl (2012) find that frustrations also relate to a lack of time and resources, causing the provision of high quality palliative care to be difficult. This is also influenced by the patients' and families' lack of awareness of the inevitability of death (Wotton et al. 2005). Nurses working with palliative care define it as an important task – part of the closing phase in the patient's life cycle (Johansson and Lindahl 2012). However, this requires knowledge and supervision for nurses in this field (ibid.). Even though nurses are having frequent contact with dying patients, their training within this field is extremely limited (Thacker 2008).

In sum, even though the role of general palliative nursing is not defined, the nurses who are working with this care have a pivotal, facilitating role. In this role there are many challenges to face, which often lead to frustrations. These challenges seem to be related to organisational factors, such as insufficient time. There also seems to be a cultural aspect, which causes the nurses to find it difficult to identify patients, as well lacking sufficient skills in the care of patients in need of palliative care, but knowledge on this is sparse in a Danish context.

Summary and Aims of the Study

Palliative care is an approach derived from the hospice philosophy which originates in the UK. The concept has been developed to address the needs of cancer patients in a terminal phase of the illness trajectory. Much of the current knowledge is derived from the UK and the US, which have a longer tradition of addressing palliative care both in hospices and hospitals. Now that there is awareness that a palliative care approach might benefit all patients with life-threatening diseases, the question is: how can this approach be practiced in settings also treating other patients than cancer patients, and especially in hospitals where half of all deaths take place? It is well-documented that cancer patients are still more likely to have access to palliative care services than patients with other life-threatening diseases and there seem to be fundamental differences in the illness trajectories.

Even though dying in hospital has been a subject of research since the 1960s, there is still evidence that the hospital and acute care settings are not regarded as ideal for dying patients. This may be explained by a clash between the curative and the palliative paradigms, as well as the organisational framework and routines in the hospital. The numerous challenges related to providing palliative care in a hospital setting are also reflected in nursing practice. The challenges seem to be related to organisational and cultural factors, but knowledge on these in a general setting is sparse.

In order to explore whether palliative care in hospitals is alienating and selective with regard to cancer patients, there is a need for more research on how the palliative care is practised in a Danish hospital setting in departments which do not specialise in palliative care.

Furthermore, it has not yet been demonstrated whether the existing evaluation programmes have had an effect on the quality of general palliative care in the hospital. Lack of validated methods and knowledge on sustainable solutions for the palliative care is missing. This is all leading to the aims of this study.

The Aims of the Study

The overall aim of the thesis is to explore the general palliative care in a hospital in Denmark. Additionally, there is a special focus on the organisation and evaluation of palliative care, as well as the culture of general palliative nursing care in selected medical departments. This is investigated through three individual studies with the following objectives/research questions which guided the study:

1. To investigate whether the organisation and evaluation of general palliative care in hospitals can be described and evaluated using existing data sources.
2. To explore the culture of general palliative nursing care, with a focus on setting, practice and the nurses' reflections in medical departments.
3. To investigate the interactions between organisation and culture as conditions for integrated generalist PC in the hospital and if possible suggest workable solutions for the provision of generalist PC.

In the following chapter the method and material used for answering the research questions will be presented.

Chapter 2: Method and Material

A descriptive convergent, parallel mixed-methods design was chosen for this study. The combination of aiming to describe the broad overall organisational approach for the entire hospital in general palliative care and exploring the nursing culture in selected departments meant that one data source would have been insufficient. This is chiefly a mixed-methods study, but since quantitative, qualitative and mixed-methods phases were used, all three will be described here. This chapter will describe the setting, the mixed-methods design, and the three individual studies with their corresponding theoretical inspiration.

Setting

In Denmark the entire health care system is mainly financed through taxation and the system is controlled by the government as well as by five regions and local municipalities. The Danish people have free choice of treatment venue.

This study was conducted at a Danish hospital. For reasons of anonymity the hospital will be referred to as the case hospital. The hospital was a large, regional teaching hospital with one hospital management and four hospital units with 29 department managements. The units were located in four different towns within close proximity.

Facts for the case hospital Denmark: (facts 2012)*

1 Hospital management
29 Clinical Specialties (department managements)
4,533 Employees (2,000 nurses)
1,059 Beds
353,792 Bed-days

**These were the facts when the data-collection took place*

The quantitative study covered the entire hospital, whereas the qualitative part of the study took place at three selected medical departments in the hospital, referred to as departments A, B and C.

The characteristics of the departments were:

Department A: This department was an inpatient department with 22 beds. There were 13 nurses and 14 health care assistants. The patient category covered the elderly clinical patient with complex health problems and multiple illnesses.

Department B: This department was a day/evening care clinic with 23 beds. There were 40 nurses and the categories of illness ranged from various kidney diseases to kidney problems and acute kidney failure.

Department C: This department was an inpatient department with 23 beds. There were 17 nurses and 6 healthcare assistants. The patients were primarily gastroenterology patients.

With 29 clinical specialties the hospital served many different kinds of patients and illness trajectories and the organisation and administration was similar to those of other hospitals of the same size in Denmark.

Mixed Methods and Design

In healthcare research the methods range from randomised controlled trials to phenomenological descriptions of life experiences (Broom and Willis 2007); this including different kinds of paradigms. A paradigm is defined as a set of basic beliefs regarding ontological, epistemological and methodological questions on the nature of reality and the nature of what can be known and how it can be known (Broom and Willis 2007; Guba and Lincoln 2005). Since the set of beliefs is different in each paradigm there is a 'split' between the positivist and the constructivist paradigm in healthcare research. The positivist paradigm is an approach that assumes that reality is objective and can be quantified, in opposition to the constructivist paradigm which aims at understanding through a belief that reality is constructed (Broom and Willis 2007). The methods used in each paradigm also differ: the methods used in positivist research (quantitative) range from randomised controlled studies to surveys, whereas the methods used in qualitative (constructivist) research consist of interviews, observations and discourse analysis (ibid.).

A third paradigm, the mixed-methods research paradigm, was first defined in the 1980s (Johnson et al. 2007). It is a tradition based on pragmatism, which aims at finding the middle ground between the different philosophical paradigms in order to find workable solutions; knowledge of both a natural physical world and the subjective social world is acknowledged (Creswell and Clark 2011; Johnson et al. 2007).

Pragmatism as a philosophical tradition was founded in the US around 1870 by William James, John Dewey and Charles Sanders Pierce among others (Johnson et al. 2007). It is a tradition which considers thought as an interaction between the person and the environment and should be used for problem solving, since the truth value of concepts lies in their utility and practical consequences. Therefore pragmatism is not concerned with the methods *per se*, but merely the consequences of the research – finding solutions which are workable and applicable.

Knowledge in pragmatism can be described as a tool for action. As described by Cornish and Gillespie: “*Unlike realism, pragmatism does not rest upon ambitious claims about knowledge reflecting an underlying reality. Unlike idealism, it rejects the idea, that the mind is the basis of knowledge, and directly opposed to rationalism it disagrees that abstract rationality is the path to reliable knowledge*” (Cornish and Gillespie 2009 p. 802). Knowledge is therefore highly linked to the practice in which it is to be used, and the evidence is linked to the practical consequences.

The emerging of Mixed Methods as a research paradigm is described as arising from increased attention to complexity in research and a call for multiple forms of evidence by policy makers and practitioners, who called for appropriate methods ; different forms of data were therefore combined (Creswell and Clark 2011). Several controversies have been described in the development process of Mixed Methods. There was a **paradigm debate period** in the 1980s, which focused on discussing the different assumptions in qualitative and quantitative research methods, and later a **research reflective period** (still ongoing), which attempts to address all the controversies that have arisen in mixed methods research (ibid.).

The mixed methods concept is described in several textbooks (Creswell and Clark 2011; Morse and Niehaus 2009; Teddlie and Tashakkori 2009) and is now a well-accepted approach to healthcare research (Creswell et al. 2004; O’Cathain et al. 2007).

There are several definitions of mixed methods research, but this thesis is inspired by the following:

"Mixed methods research is a research design with philosophical assumptions as well as methods of inquiry. As a methodology, it involves philosophical assumptions that guide the direction of the collection and analysis and the mixture of qualitative and quantitative approaches in many phases of the research process. As a method, it focuses on collecting, analyzing and mixing both quantitative and qualitative data in a single-case study or series of studies. Its central premise is that the use of quantitative and qualitative approaches, in combination, provides a better understanding of research problems than either approach alone" (Creswell and Clark 2011 p. 5).

However, the different approaches in mixed methods should be acknowledged and addressed in respect to their paradigm. In the literature the different paradigms have been described as a "war" between the constructivists and the positivists (Denzin 2010), claiming that the different paradigms cannot be combined owing to the differences between their underlying paradigm assumptions.

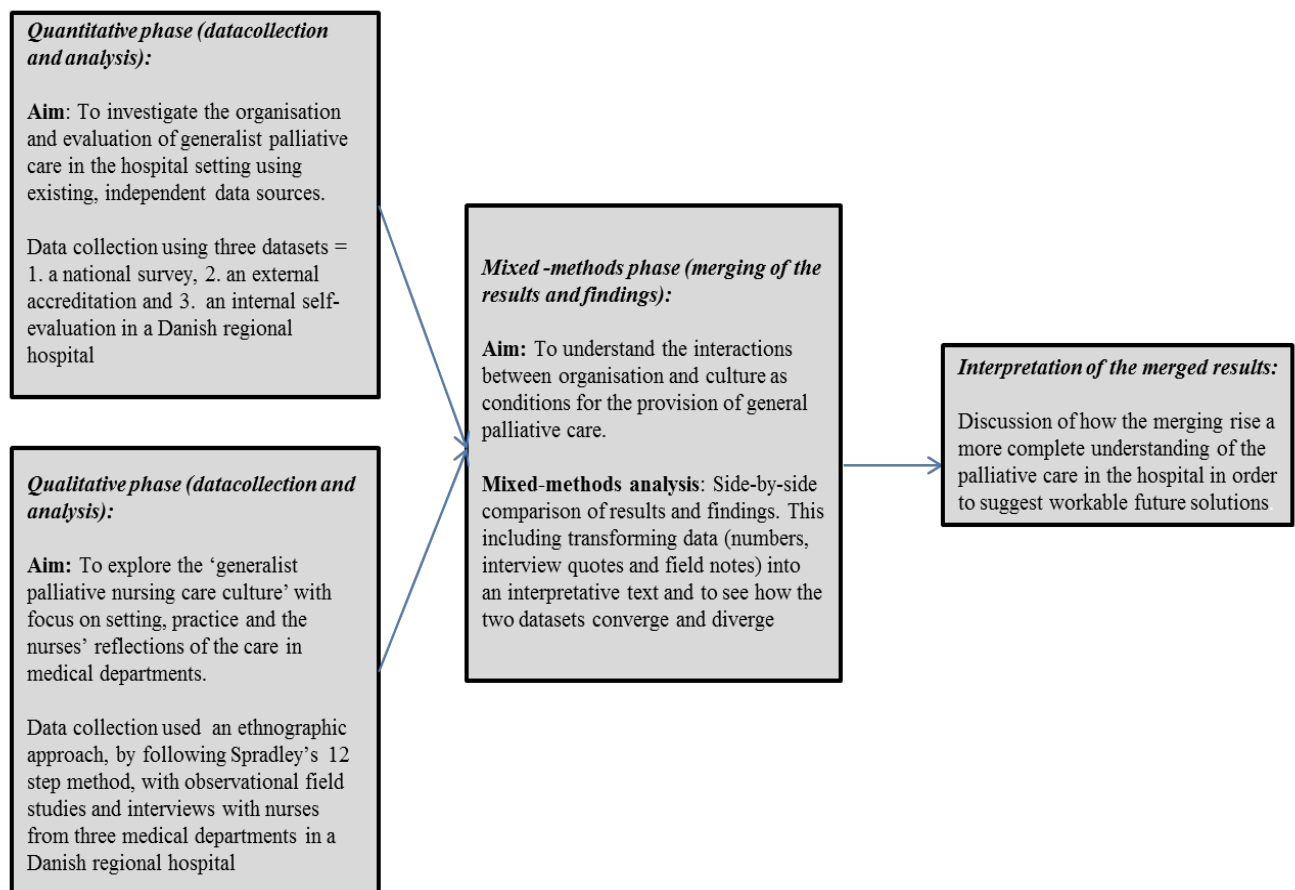
Rather than staring blindly at the methodological challenges, a combination of quantitative and qualitative methods may enhance the utility of the trial results and in the end will affect the palliative patient positively (Flemming et al. 2008).

As the terms "mixed methods" and "triangulation" are often confused and used as synonymous definitions, their use in this study will be clarified. Denzin described in 1989 four types of triangulation: across data sources, theories, methods and two types of methodological triangulation: "within-method" and "across-method" (Denzin 1989). Within-method triangulation uses more than one method of data collection within the same design and is used for measuring the same variables. Across-method triangulation uses both quantitative and qualitative methods for the data collection. It has been seen that across-method triangulation seems to be the most dominant type (Casey and Murphy 2009) and is mostly called mixed methods. In this study both across data sources, within-method and across-method triangulation were used. The within-method triangulation and across data sources were used in the quantitative as well as in the qualitative study, as several methods and datasets were used. The overall approach in this thesis was across-method, since a mixed-methods design was chosen to illuminate the overall objective.

The use of mixed methods in palliative care is becoming more and more frequent because it resonates with the complexity of the care (Seymour 2012) and a recent meta-synthesis by Evans et al. (2013) found that this complexity requires knowledge from multiple sources to develop and evaluate the care.

In order to investigate the three objectives in this thesis a convergent, parallel mixed-methods design was chosen (Creswell and Clark 2011). This included concurrent quantitative and qualitative phases and a phase of mixed-methods merging. Figure 1 visualises the mixed-method design used for the objectives in this thesis:

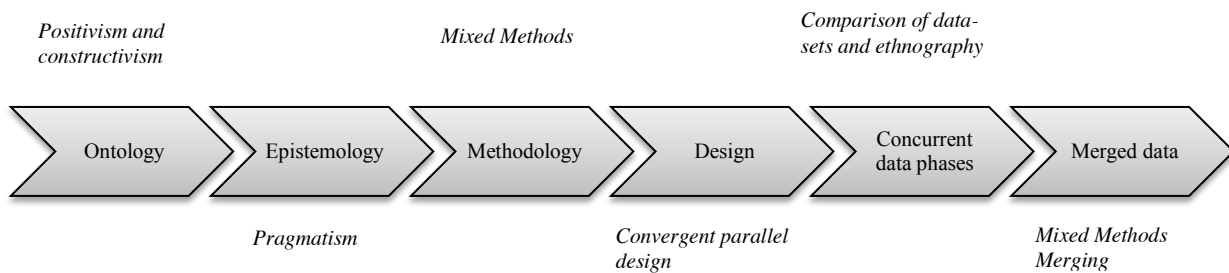
Figure 1: Mixed-methods convergent parallel design (inspired by Creswell/Clark)



In this design each dataset was equally prioritised, collected and analysed separately, and then combined in a mixed-methods merging.

Figure 2 visualises the ontology, epistemology and methodology used in this thesis.

Figure 2: The ontology, epistemology and methodology of the study



As this thesis is based on an epistemological pragmatic approach, the use of theory and analytical tools is closely linked to practice and the usefulness of the results and findings. As pragmatism is based on an abductive reasoning (Johnson and Onwuegbuzie 2004), with the ideal of finding the most likely explanation to a given phenomenon, the theories were chosen on the basis of the data material and the research questions and were not deductively applied over the data material from the start. The use of analytical tools and corresponding theory are described under each of the phases.

Quantitative Phase (Paper 1)

The first objective was aimed at investigating how existing data sources can describe the organisation and evaluation of general palliative care. This came from the hypothesis that a triangulation of independently collected data would provide a detailed picture of the organisation and evaluation of generalist palliative care in hospitals. This was tested by using three existing, independently collected data sources. Details on the quantitative study can be found in Paper 1 (Bergenholtz et al. 2015a).

Paradigm – Positivism

The paradigm in this study can be described as positivist. As described earlier, the positivist paradigm is linked to an objective world view in which knowledge is obtained by objective data and testing hypotheses in order to generalise and predict cause and effect (Collin and Køppe 2014; Creswell and Clark 2011). This tradition is linked to the biomedical paradigm and its strength lies in its ability to test hypotheses and generalise research results. The results also have the strength of being relatively independent of the researcher (Johnson and Onwuegbuzie 2004). Furthermore, this kind of research is less time-consuming and is useful for research involving large data samples. The positivist paradigm is also what is called the quantitative paradigm, as it aims to quantify information in order to gain knowledge of the research topic by testing hypotheses’.

Method and Material

To test the hypothesis a retrospective descriptive quantitative study was chosen, set in the case hospital. In the period from summer 2011 to spring 2012, the hospital was the object of three different studies/evaluations, from which data on the hospital’s approach to delivery of general palliative care could be extracted. The datasets, which all illuminated aspects of organisation and evaluations on general palliative care, were identified by the candidate in collaboration with the supervisors as well as the quality unit at the case hospital. The methods used were a comparison of the three datasets.

The material used for this study consisted of one hospital management and 29 department managements from the case hospital. All of the departments were included. In the hospital’s self-evaluation (dataset 3) only 23 departments with 56 sections were subjects for the evaluation. This was because the quality unit at the hospital did not consider that two medical and four miscellaneous departments (1 audiology, 1 ophthalmology and 2 emergency rooms) were relevant to the use of the palliative standard.

The three datasets were:

Dataset 1: The external accreditation procedure by IKAS

At the case hospital, a national accreditation procedure by the ‘Danish Healthcare Quality Programme’ – DDKM (a Danish abbreviation for ‘Den Danske Kvalitets Model’) – was conducted in June 2011. The procedure was performed by The Danish Institute for Quality and Accreditation

in Healthcare, called IKAS, who manage, develop and plan the DDKM programme (The Danish Institute for Quality and Accreditation in Healthcare (IKAS) 2009). The national accreditation aims to: “1: Improve the quality of the patient trajectory, 2: Promote the development of quality in terms of the clinical, the organisational and the patient’s, 3: Make the quality of the health service visible (The Danish Institute for Quality and Accreditation in Healthcare (IKAS) 2009). It has developed a series of 104 standards (version 1), palliative care being included in Standard 2.19.1: “Palliative care of the incurable patient and the patient’s relatives”. To comply with the standard, two indicators must be fulfilled: 1. the presence of guidelines, and 2. managers and staff must be familiar with and use those guidelines.

Dataset 2: The PAVI-survey

The case hospital was also part of a nationwide survey which aimed at mapping the organisation and structure of Danish hospitals’ provision of general palliative care (Jarlbaek and Timm 2015). The survey was designed by the Knowledge Centre for Rehabilitation and Palliative Care (PAVI), which sent out the questionnaires and received the responses. All clinical departments with patient contact in Denmark received a questionnaire divided into different themes concerning the organisation and structure of palliative care (Appendix 1). The national overall response rate among the 410 departments was 78%. A report of the full national survey can be found elsewhere (Jarlbaek and Timm 2015). Data from the case hospital were extracted for this study.

Dataset 3: The hospital’s internal evaluation

At the case hospital an internal self-evaluation of the palliative standard was performed as a part of the accreditation process (dataset 1), as recommended by IKAS. The self-evaluation consisted of two parts:

- 1: A self-evaluation performed by key quality personnel in the clinical departments
- 2: An audit conducted by a survey corps in selected departments.

The internal survey aimed to evaluate to what extent the palliative guideline had been implemented, and to identify needs for improvement to fulfil the indicators for the accreditation which takes place every three years.

Analysis of the Three Quantitative Datasets

This study use an across datasets and within-method triangulation (Denzin 1989) to describe and identify concordances and/or inconsistencies in the organisation and evaluation of general palliative care. Descriptive statistics were used to present the results of the triangulation and comparison. Descriptive statistics, in general, describe the main characteristics of a known population or dataset; it is distinguished from inferential statistics, which aim to conclude on a whole population based on a dataset from a representative sample (Andersen and Matzen 2005). Microsoft Excel was used to compare the datasets systematically.

In this study the comparison was carried out in four steps:

First, in order to triangulate the data and to compare the departments concerned, the latter were categorised by type of clinical specialty in accordance with PAVI's breakdown from the national survey. These were medical, oncology/haematology, surgical, paediatric, anaesthesiology, gynaecology/obstetric and miscellaneous.

Second, since the three datasets had different concerns to address, a search for common answers across the datasets was conducted. It was found that the evaluation of the palliative standard was used in all three datasets and became an object for comparison. However, it was evident that the organisational factors could only be described by the PAVI-study, so this was included as well to answer the research question.

Third, the departments with discrepancies in the answers and the palliative standard were presented. Fourth, the answers to the PAVI-survey from the hospital management and department managements were compared in order to identify how the general palliative care was organised at the hospital.

Qualitative Phase (Paper 2)

The qualitative phase aimed at exploring the general palliative nursing care culture with a focus on setting, practice and the nurses' reflections of the care in medical departments. Further details can be found in Paper 2 (Bergenholtz et al. 2015c).

Paradigm – Constructivism

As described in the Mixed Method and Design section, constructivism as a theory of knowledge argues that knowledge is generated by humans (social actors) in their interaction of meanings and experiences, and is created rather than discovered by the mind (Denzin and Lincoln 1998). Given the dynamic nature of culture, where human beings act, interact and handle things on the basis of what these things mean to them, there is an implication of multiple realities the truth created between these realities (Denzin and Lincoln 1998; Guba and Lincoln 2005) the constructivist approach fits the second objective of this thesis. As the researcher's position is of importance when using this approach, preconceptions will be presented below.

Preconceptions – The Researcher's Position

In qualitative research, reflections on the researchers' positions and preconceptions are made as part of the reflexivity, in order to make the research process more transparent to the reader (Crabtree and Miller 1999; Malterud 2008). In this study, such reflections have been applied to the supervisors as well as to the PhD candidate, in an attempt to help eliminate blind spots and to present the motivation for doing the study.

Both academic supervisors in the study have a background in the healthcare professions (nurse and medical doctor). The principal supervisor (nurse) was involved in the establishment of the first Danish hospice in 1992 and is currently engaged in a study regarding palliative care needs among young people with cancer. The co-supervisor (medical doctor) serves as a consultant in Oncology and is a palliative care senior researcher.

In the following section the position and preconceptions of the PhD candidate will be unfolded in the first person and in more depth:

“I am a professionally trained nurse and I have previously been employed in medical departments primarily for patients with lung diseases. Although it was other categories of illness that were being treated in the specific departments, in this thesis, I already knew the medical terms and the organisation of the work. I therefore did not spend time on understanding what was being talked about or who was who, but I was able instead to focus on studying the palliative culture. I saw this as an advantage. In my earlier employment as a nurse I was interested in the palliative care of

COPD patients and I wrote my thesis on this topic, which also led me further in my PhD at the hospital.

My motivation for undertaking this study was therefore to investigate whether and how the care for all palliative patients with life-threatening diseases in hospital could be improved. In my previous work I often took care of dying patients and I noticed that both my colleagues and I tried to ensure a “good death”, as we defined it. It was important to me to ensure that all dying patients experienced a “good death”, but I often saw that patients with COPD received less relief than lung-cancer patients. My interest in this increased as I had a strong desire to provide “good care” for all patients. My motive for investigating this topic was not simply to find out whether I was right, but to open, explore and discuss the field of general palliative care in order to provide the best possible care for all patients dying in hospital.

A challenge in my fieldwork was to observe palliative care. How do you do that? It was almost a relief when there was a dying patient in the departments because it was then articulated that palliative care was being provided. My observational framework for focused observation crumbled as so many other activities were going on. This was a source of frustration, which I solved by writing down almost all situations, leaving me with “too much” data. However, this frustration also partly became the answer to my objective: so many things are going on in the medical departments that there is little room for palliative care.

During the course of my PhD I also had two personal experiences of the subject – two dying family members. This may have affected my view of palliative care in hospital, but was discussed with my principal supervisor, so that it did not have a controlling influence on the results of the studies”.

Theoretical inspiration

The exploration of the culture in general palliative nursing care was inspired by the concepts of culture and ethnography, which will be presented below.

- Culture and Ethnography

Culture as a concept has a variety of definitions and can be characterised as elusive and difficult to define (Duffy 2001). It is often described as what is shared by the members of a culture. In this study, the definition from the American professor in ethnography James P. Spradley: “...the

acquired knowledge people use to interpret experience and generate social behavior” (Spradley 1980 p. 6) is used. The use of the term “acquired” instead of “shared” knowledge implies that members of the same group may interpret situations differently. The difference between the terms is described by Spradley as: *“We have merely shifted the emphasis from these phenomena to their meaning”* (Spradley 1979 p.6). In this sense it is merely the meaning of situations which defines the culture as: *“...a system of meaningful symbols”* (Spradley 1979 p.6).

When describing a culture, cultural knowledge, behaviour and artefacts are of importance. The artefacts refer to the things people in a culture make use of. Since behaviour and artefacts are observable, these only represent a small part of the whole. Through cultural analysis one can discover how cultural knowledge (acquired knowledge) interprets the behaviour and use of things. Cultural knowledge generates behaviour through interpretation (Spradley 1980).

One way to study culture is through ethnographic method; Franz Boas (Boas 1922) and Bronislaw Malinowski, who were pioneers of social anthropology in the 20th century, describe the goal of ethnography as to grasp the natives’ point of view (Spradley 1979). Malinowski’s monography (Malinowski 1922) is based on what we today call “participant observation”. He was touted as the founder of modern anthropological fieldwork (Hastrup 2010a), which has been further developed by a number of his successors. However, the field of ethnography has moved from studying remote and primitive cultures, to currently being everywhere and to a greater extent describing social and cultural differences (Hastrup 2010b).

Ethnography as methodology has also been applied in nursing studies (Polit and Beck 2010). As most researchers in nursing have no educational background in anthropology, the term ‘focused ethnography’ has been adopted in health care and nursing research (Cruz and Higginbottom 2013; Higginbottom et al. 2013). Focused ethnography performed by healthcare professionals (nurses) differs from the ethnography conducted by anthropologists (Kleinman 2015; Roper and Shapira 2000; Thorne 1991) as it is modified to meet the needs in healthcare research (Morse 2007). Focused ethnography tends to be conducted over a shorter time-span, its observations in healthcare research are more focused, and the nurses involved bring background knowledge to the field (Knoblauch 2005). The debate on separating the focused ethnography from anthropological ethnography is ongoing (Higginbottom et al. 2013), and the term of focused ethnography is well-

accepted in nursing research (Cruz and Higginbottom 2013). As the approach suggested by Spradley is regarded as useful in all studies of cultures,- the term ‘ethnographic study’ is used in this thesis- in full awareness of the debates concerning this term.

Method and Material

An ethnographic study was chosen to explore the second objective. As this objective was aimed towards an exploration of the culture, this method was chosen in order to discover how cultural beliefs and practices shaped a palliative nursing care culture. The methods consisted of fieldwork; 1. participant observation (observational study), including informal interviews with nurses, other health-care professionals and relatives; 2. formal interviews with nurses.

The ethnographic study took place at the case hospital in the period September 2012 – February 2013.

At the case hospital three departments were selected by purposeful sampling (Malterud 2008). This was done in order to highlight the nature of the problem as effectively as possible and to focus on departments relevant to general palliative care. The sampling was directed towards the best information rather than representativeness, as the qualitative study aimed to explore the general palliative care rather than generalise the findings. The selection was therefore guided by the answers in the national survey conducted by PAVI (the quantitative phase) in selecting departments which responded that they had palliative patients at a general level. The palliative specialised departments were therefore excluded. As all of the medical departments in the PAVI-survey responded that they had palliative patients, the medical departments were chosen for the study.

Furthermore, the selection should have covered the entire hospital (four units), but as the fourth hospital closed down during the research period only three participated in the ethnographic study.

The three departments chosen were located in three physical units – A, B and C. Interest in and acceptance of participating in the study were indicated by the three head nurses, who established contact to the three departmental nurses; the latter served as the gatekeepers (Crabtree and Miller 1999) throughout the study.

- Observational Study

The observational study was inspired by Spradley and his 12-step developmental research sequence (Spradley 1979; Spradley 1980). Ethnography is focused on describing a culture and grasping the

natives' points of view (Spradley 1980). Ethnography is distinguished in an emic/etic point of view, where the etic point of view argues that the meaning of an actor's behaviour is best interpreted by the researcher in their own theoretical dimensions (Robertson and Boyle 1984). Spradley advocates for an emic approach, which requires that the researcher enters the informant's world and observes how he/she describes and identifies their reality (Parfitt 1996; Robertson and Boyle 1984).

Spradley's theory provides a systematic and rigorous approach in collecting and analysing data, which is particularly useful for a newcomer to the field of ethnography. Spradley has been used as inspiration for many observational studies, but his analysis has also been criticised for its time-consuming and complex stages (Parfitt 1996).

The observational study was conducted by the candidate and focused on general palliative nursing care in terms of the setting, practice and the nurses' reflections of the care in medical departments. The study involved: 1. Observational studies at the three departments; two weeks in each department, in total 156 hours; and 2: Informal interviews (N=21) with nurses, doctors, patients and relatives. The informal interviews focused on the nurses and their interactions and collaboration with other healthcare professionals, patients and relatives

The observations were based on an observational framework inspired by Spradley, in which several dimensions were observed: space, object, act, activity, event, time, actor, goal and feeling (Appendix 2). This framework was used as inspiration for what to observe. As recommended in the international and national recommendations for palliative care (National Board of Health 2011; World Health Organization 2013; World Health Organization 2014) the observations were guided by the premise that palliative care should involve all patients with life-threatening diseases.

The tool used in the study to capture the observations was field notes. First a condensed account was made on small pocket-cards in the hall, in the staffroom, in the corridor and in the office. These notes were written up as soon as possible the same day to form an expanded account (Spradley 1980), since the condensed field notes were often short and sometimes difficult to read. It was these expanded accounts which were subject to subsequent analysis. Altogether, 83 pages of expanded accounts were written. The accounts included both grand tour descriptions (*ibid.*), in which the general attributes of the department – its appearance, structure and organisation – were documented

in order to provide an overview of the field where the observation took place. Mini-tour observations (focused observation) were also conducted.

The observation was from passive to moderate participation (ibid.). To be “a fly on the wall” in the field was often impossible in a ward, where all attention became directed towards the “outsider” (the candidate), which was why participation was sometimes moderate. The candidate’s own experience of nursing made it possible to transition smoothly between passive and moderate participation.

- ***Interviews (Focus Group and Individual)***

The ethnographic study also consisted of focused ethnographic interviews (Spradley 1979) with 18 nurses from the three departments. The reason for choosing focus group interviews as the method (Malterud 2012; Morgan and Spanish 1984) was that the aim of the objective was to capture both the culture of general palliative care practice as well as reflections on this. Since the reflections were not seen during the observational study these interviews were used as further elaboration of the work on general palliative care. As part of an ethnographic study, it made sense to take an interest in the creation of common experiences and attitudes in the field for the focus group interview (Kitzinger 1995; Malterud 2012). The original plan was to conduct focus group interviews in all three departments, but one department (department A) could not provide more than one nurse at a time, so it was necessary to conduct four individual interviews instead.

The nurses were selected by the gatekeeper by convenience sampling (availability and access) (Crabtree and Miller 1999) of those who were on duty on the day of the interview and who were able to be away from patient care in the given time period. The respondents were all women, some newly qualified and others experienced. Nurses with more than two years’ experience of the department were considered ‘experienced’ and nurses who had qualified within the previous six months were considered ‘newly qualified’ (Appendix 3).

A semi-structured interview guide was used (Appendix 4-5), covering aspects of the general palliative care which had not been observed in the field study.

In the focus group interviews the candidate was the moderator and the main supervisor was the observer. Since the candidate had performed the observational study prior to the interviews and as earlier research has shown that the moderator role may be influenced by the different positions (Reventlow and Tulinius 2005), the observer's role was to observe and point out the moderator's blind spots.

The individual interviews were conducted solely by the candidate.

All interviews were audiotaped and transcribed verbatim. They lasted from 21 – 80 minutes. The transcription was carried out by a non-healthcare professional, but as part of the analysis the candidate listened to the recordings a number of times after they had been transcribed.

Analysis of the Qualitative Data

The analysis of the qualitative data was conducted with inspiration from Spradley's ethnosemantic analysis, including a domain, a taxonomic and a componential analysis, in order to derive cultural themes. The aim of the ethnographic analysis was to grasp the patterns which existed within the culture and to see find a meaning in social situations (Spradley 1980). Both the observational study and the interviews were included in the analysis. Even though Spradley presents a 12-step developmental research sequence, only four of these steps form the actual analysis and will be presented here. All 12 steps are presented in Paper 2.

Domain analysis (step 6) is the introductory analysis, in which the semantic relationship between the cover terms and the included terms was identified and formed the basis for the domains. In this step the focus is not on the meaning of the text but the semantics (Spradley 1980). Each department was analysed separately at this step.

From the condensed accounts and transcripts of the interviews the words were extracted by thorough reading and coding words, quotes, situations and reflections line-by-line from the data material. The words were identified by the candidate.

These words are called *included terms* and the domain analysis aims to derive the semantic relationship between the included terms and the *cover term*, which gives rise to the domains for each department. An example of the domain analysis is described below in Table 1. The example, on the domain "The good death", comes from department A. The domain arose through the analysis

and is related to what the nurses understood as a good death in their department. Below it, the semantic relationship in the domain is illustrated, consisting of included terms and cover terms:

<i>Table 1. Example of domain analysis on the domain “The good death”</i>		
<i>Included Terms</i>	<i>Semantic Relationship</i>	<i>Cover Term</i>
Calm. Respect. Serious. Competencies. Time. Candles. Peace. Physical contact. Relatives. Morphine. No symptoms. Clarified. Daily rounds.	is a kind of	The good death

It should be noted that this domain is only used as an example and did not constitute one of the main findings, since it was only present in one department.

As the cover terms and included terms together are called a *domain*, the number of domains identified was: Department A: 25 domains; Department B: 25 domains; Department C: 32 domains. These are illustrated below:

Domains in department A (25 domains):

Spiritual care, Wishes for the future, Wishes about death, Change from active treatment to palliative care, Interdisciplinarity/collaboration, Time, Symptom relief, Nurse’s framework, Pain, Guidelines, Relatives, Prioritising the palliative care, Care for the dying, Palliative care, Organisation of the work, Competencies, Communication, Physical environment, Physical contact, Death, Discussions of palliative care, Diagnosis/ prognosis, **The good death**, Treatment at the hospital, What the department offers

Domains in department B (25 domains):

Spiritual care, Wishes for the future, Interdisciplinarity, Time, Rituals , Guidelines, Relationships, Relatives, Prioritising of care, Conducting palliative care, Palliative patients, Palliative care, Change from active treatment to palliative care, Organisation, Human abilities, The machine, Culture in department, Competencies, Communication, Instrumental nursing, Physical environment, Ethics, Documentation, Being a nurse, Being a patient

Domains in department C (32 domains):

Unequal practice, Interdisciplinarity, Time, Symptom relief, Hospital vs hospice, Illness trajectory, Collaboration, Rituals, Guidelines, Relationships, Relatives, Prioritising, Palliative care, Change from active treatment to palliative care, Organisation, Organisation of care, Key person, Nonverbal behavior, Competencies, Communication, Hierarchy, Physical environment, Wishes for the future, Fix-it nurse, Professional discussions, Ethics, Nutrition, Documentation, Diagnosis, Reluctance, Level of treatment, Actors in palliation

After identifying the domains from the text, the next step in the analysis is the taxonomic analysis.

Taxonomic analysis (step 7): The included terms from the domain analysis were further systematised in order to derive the internal organisation in the domains. The taxonomic analysis was supported by using the qualitative data analysis software NVivo vs 10. This programme was used as a database to store the data and the analysis was not performed using NVivo. The software was excellent for keeping track of all the domains, but the analysis was not done using the tools provided by NVivo. Since this was a creative process the candidate felt restrained by using only NVivo. The actual analysis was done on paper, with words and sentences cut out and laid out on the floor.

Once more, the domain “The good death” is used as an example for this analysis:

Table 2. Example of taxonomic analysis on the domain “The good death”

<i>Cover term</i>		<i>Systematised included terms</i>
The good death	Physical space	Calm. Serious. Candles. Peace.
	Being present	Relatives. Physical contact. Respect
	Addressing the symptoms	Daily rounds. Morphine. Competencies.

Componential analysis (step 8): In this step a systematic search (condensation) for components of meaning formed the cultural categories (components of meaning) (Spradley 1980). The componential analysis is the most in-depth analysis which can be done by specific domains. It was

chosen to perform this on the domains which overlapped all three departments. This resulted in five cultural categories, which were derived from the domains:

1. The hospital department.
2. Palliative care and dying in the hospital.
3. The patient in the hospital.
4. The role of the nurse.
5. Potential changes and specific wishes regarding future work with palliative care.

Each category contained domains from the previous step in the analysis, but this was a form of condensing, which should add meaning to the research question on the culture of general palliative nursing.

Discovering Cultural themes (step 9): The overall aim of the analysis was to discover cultural themes. These themes should provide an overview of the culture of general palliative nursing care. The themes covered statements, stories (cases), conflicts, contradictions, relations, problems, barriers and potential for improvement.

These cultural themes were the findings of this study and are presented in Paper 2.

Mixed Methods Phase (Paper 3)

After the two parallel phases described above the qualitative results and the quantitative findings were merged into an overall interpretation in the third phase (Creswell and Clark 2011). This was done to address the objective on understanding the interactions between organisation and culture as conditions for the provision of general palliative care in order to suggest relevant future solutions. Details can be found in Paper 3 (Bergenholtz et al. 2015b).

Paradigm – Pragmatism

As described earlier, since weaknesses exist in both the quantitative and qualitative paradigm, the pragmatic paradigm seeks to merge the paradigms of a natural, physical world with the subjective, social world in order to gain expanded knowledge and to find sustainable and workable solutions (Bekhet and Zauszniewski 2012; Casey and Murphy 2009; Creswell and Clark 2011; Johnson et al. 2007; Johnson and Onwuegbuzie 2004; Lipscomb 2008). The weaknesses of quantitative research

(paradigm) is that it is difficult to grasp whether the categories and understanding that the researcher derives from the analysis are in accordance with the object studied (Johnson and Onwuegbuzie 2004). This may be a cause of bias if the researcher does not have all phenomena in mind, and there is a risk that the researcher's picture of reality can become oversimplified. Furthermore, the weaknesses in qualitative research include a lack of generalisability and the research can be influenced by the researcher's personal blind spots, leading to a false image of reality (Creswell 2013;Denzin and Lincoln 1998;Malterud 2001). The merging of methods and paradigms aims to illuminate a given topic from several viewpoints and thereby minimise the weaknesses in individual approaches.

Method, Material and Analysis

In this thesis the mixed methods merging included both the quantitative and the qualitative material and the results and findings were mixed during the interpretation as the final step of the research process. The samples have been described in the quantitative and the qualitative phases in the previous sections and will not be introduced here.

As suggested by Creswell and Clark (2011), the process of mixed methods and merging the two datasets was conducted through seven steps:

1. ***Collection of quantitative and qualitative data.*** (Described in Phase 1 and 2).
2. ***Independent analysis of the quantitative and qualitative data.*** (Described in Phase 1 and 2).
3. ***Specification of the dimensions by comparing the results from both studies.*** This step included a search for dimensions that were common to both studies. This was done by examining all of the quantitative and qualitative material again. It should be noted that since the aims of the studies were different, this phase was difficult, time consuming and involved many discussions between the candidate and the principal supervisor.
4. ***Specification of which information would be compared across the dimensions.*** When the above dimensions were identified, data transformations followed in order to compare the results. These were done by transforming the data presentations from each study into a meaningful text which could be analysed. This phase also included a large amount of data reduction, since only very few dimensions of the total data material were comparable. The

comparison of the data followed a side-by-side comparison for merged data-analysis (Creswell and Clark 2011). The dimensions common to each study became the subject of comparison. These dimensions were: a) General palliative care as a priority at the hospital and b) Knowledge and use of palliative care clinical guidelines.

5. ***Completion of the quantitative and qualitative data analysis to produce required comparison information.*** As both the quantitative and qualitative analysis had been completed before the comparison a new search was conducted for overlooked phenomena in the two datasets.
6. ***Representation of the comparison.*** The merged results are presented in Paper 3
7. ***Interpretation of how the merged results answer the mixed methods question.*** The mixed methods objective for this thesis was discussed between the candidate and the supervisors in the light of the merged results which are partly presented in Paper 3 and partly in the expanded discussion in this thesis.

The challenge for this mixed methods merging was to provide new knowledge and to answer the mixed methods research question, rather than just being a repetition of the two datasets. It was a complex process. Therefore the three-perspective analytical framework of organisational culture by the American Professor of Organisational Behaviour, at Stanford University Joanne Martin (2002) was applied in order to understand and elaborate on the results which are presented in Paper 3.

Theoretical Inspiration for Discussion

In order to gain a broader understanding of the culture of general palliative nursing care and to address the different organisational levels within the hospital, the concept of organisational cultural theory has been included as a theoretical inspiration in the discussion. This was done in order to discuss how these levels act and interact, what pitfalls there may be and to illuminate the interactions between organisation and culture as conditions for the provision of generalist palliative care in the hospital.

- Organisational Culture

The history of organisational theory is influenced partly by a sociological inspiration as well as by management theory (Hatch 2006). The sociological approach was shaped by Max Weber, Émile

Durkheim and Karl Marx, who were interested in how industrialisation and organisations influenced the nature of work for the workers. The management theory funded by Frederick Taylor focused merely on the problems faced by managers in the organisations (ibid.). In the more recent organisational theory, known as Human Relations Theory, Elton Mayo identified the importance of the human factor and social needs in organisations, when studying what affects efficiency (Grey 2009).

When examining an organisation from a cultural perspective the investigation attempts to explain why things are done the way they are in the organisation. As explained by Martin (2002), cultural manifestations (the practices of a given culture) are of interest since they provide information on the patterns presented by the culture. The term organisational culture has an enormous variation in usage, and there is no broadly agreed definition for it in the literature. In this thesis the Swedish Professor Mats Alvesson's definition is included and he states: "*I use the term "organizational culture" as an umbrella concept for a way of thinking which takes a serious interest in cultural and symbolic phenomena*" (Alvesson 2002 p.3).

Alvesson's description of organisational culture acknowledges the variety of meanings but points towards the cultural and symbolic phenomena. Studying organisational culture involves exploring different kinds of symbols, rituals, myths, stories, values and assumptions about social reality which exist within an organisation (Alvesson 2002). The organisational theorists (Alvesson 2002; Martin 2002; Schein 1984) who inspired this study all approach organisations from an ethnographic angle.

There are different levels to address in the investigation of the development of shared values and opinions in the organisation: the macro and the micro level (Alvesson and Kärreman 2011). On the macro level the discourse concerns the global, international, national and societal levels, whereas the micro level describes the individual discourse taking place in individual situations. This thesis primarily takes an interest in the micro level.

In this thesis, Martin's three-perspectives analytical framework of organisational culture (Martin 2002) will serve as a platform since it provides an approach that incorporates several different perspectives on organisational culture. The perspectives describe patterns of meaning which exist in the organisation, including those that are in harmony, those that are in conflict and those that are contradictory (ibid.).

- ***Three Perspectives on Organisational Culture***

The framework from Martin will provide an angle in the discussion on the pitfalls in the organisation where palliative care is provided.

In studying organisational culture, three general and different theoretical perspectives have been described as fundamental principles at “war” with each other (Martin and Frost 2012).

The three perspectives are (Martin 2002):

1. ***The Integration Perspective:*** Studying an organisational culture from this perspective focuses on the shared consensus within a culture. A culture is structured by consensus, consistency and clarity among the participants belonging to that culture. The patterns of shared beliefs in the organisation are what shape this and ambiguity is excluded. Deviations from consistency are seen as a problem for the organisational culture
2. ***The Differentiation Perspective:*** This perspective focuses on ambiguity within a culture. There is still a definable culture within the organisation, but it is characterised by high complexity and different kinds of identities. When studying organisational culture with this view there is a focus on inconsistency and how the different subcultures interact (and/or conflict) with each other in the organisation. There may be harmony (consensus) within the different subcultures. The cultural manifestations have inconsistencies, such as being policy-inconsistent despite having an overall policy.
3. ***The Fragmentation Perspective:*** This perspective is difficult to grasp since it is defined by ambiguity, which is difficult to conceptualise. This perspective sees cultural manifestations as neither consistent nor inconsistent, but ambiguously related to each other, such that ambiguity becomes the core of the culture. Focusing on ambiguity in a culture is characterised by high complexity and different identities.

Most studies use only a single perspective, but in order to reduce the risk of blind spots embedded in each perspective Martin advocates for using all three perspectives when describing the culture of an organisation. This also helps to expand the variety of meanings which exist within the concept of organisational culture and to challenge the assumption that culture is only what is shared.

According to Martin (2002), culture is constituted by both what is shared (consensus) and also by what is fragmented and ambiguous. This thesis has attempted to follow Martin's suggestion to include all three perspectives in order to explore and discuss interactions between organisation and culture as conditions for the provision of general palliative care in the hospital (elaborated in Paper 3 (Bergenholtz et al. 2015b)).

Ethical Considerations

The study was performed according to the Declaration of Helsinki (The World Medical Association 2013). The Danish Data Protection Agency registered the study (NR: SN-36-2011). Formal ethical approval by the research ethics committee system was not required by Danish law (nr. 593 of 14/06/2011) owing to the nature of the study (i.e. a non-trial study that did not include biomedical material or biomedical data).

The hospital management gave permission for the study, and all the participating departments, as well as the nurses involved, gave their consent prior to the use of evaluation information, the observations and the interviews. They were fully informed of the purpose of the study and were assured of anonymity and confidentiality in any subsequent publications. For this reason the specific departments have been anonymised as well. Specific information (Appendix 6) was sent to all staff in the departments prior to the observational study.

The ethical principles described in the Declaration of Helsinki (The World Medical Association 2013) to protect the privacy and confidentiality of the participants were followed throughout the study.

As described by Casarett and Karlawish (2000), research in palliative care can be characterised as ethically challenging, as the patients involved are vulnerable. Even though Casarett and Karlawish argue that special guidelines for research in palliative care are not needed, certain reflections on this matter were made during the study and are described below.

During the observational study, I (the PhD candidate) followed the nurses around in the departments, meeting both patients and relatives. I always introduced myself and told them that I was observing the work of the nurse in relation to my research on working with patients with life-threatening diseases. As described by Addington-Hall (2002) "palliative care" is an emotionally loaded term, often related to the concept of death. Furthermore the term may be a foreign word for

others than health care professionals. Due to these facts I consciously avoided using this term with patients and relatives.

In every situation I asked the patient or the relatives for permission to be present with the nurse and watch her activities in the work of patients with a life-threatening disease. Everybody accepted my presence and it did not seem to be a problem for the patient or the relatives.

I also observed particularly sensitive and ethically challenging situations, where dying patients were unconscious and could not give their consent for me to be present. In these situations the relatives were asked and they all accepted and were also happy with my presence since I had more time to listen to them than the nurses. In a few situations I stayed in the room with the patient and relatives, for example if the nurse had to leave to collect something, and it was evident that the nurse was relieved that I could stay with the patient or the relatives as she had a lot of other work to do, and could not spend more than a few minutes in the room.

In this study the ethical considerations restricted not only to the palliative care patients but also in relation to the participating nurses. Even though the observational studies were restricted to two weeks at each department, it felt like my presence was quickly accepted by the nursing group and a relationship of trust was established. This also meant that the nurses shared confidential information with me. For example, one nurse expressed frustration about the workload and the management, and then afterwards told me that this was confidential. This information was respected and was not included in the field notes.

Before my period of observation began, written information concerning the study was disseminated to the nurses by the departmental nurse. However, in some departments I noticed that some of the nurses seemed to find it uncomfortable to have me around them all the time. In these cases I explained to them openly that my observations were an exploration of the palliative care, since it was an unexplored field; I explained that my intention was not to judge whether it was practised good or bad. This seemed to make the nurses comfortable and accepting of my presence.

Furthermore, during the observational study I was wearing a white uniform like the nursing staff, as had been suggested by the departmental nurses, which allowed a degree of blending in as an important part of the insider-outsider relationship in ethnographic nursing studies (Allen 2004). The

challenges that arose during the study, with respect to the different roles, will be discussed in the section on methodological rigour.

Furthermore in the focus group sessions and during the individual interviews many patient stories and names were shared. These stories were written without any characteristics that might lead to recognition of the patients or health care professionals.

Chapter 3: Results and Findings

The results and findings are all presented in three papers, and this chapter will shortly summarise these. The papers are all attached in full.

Paper 1: Organization and Evaluation of Generalist Palliative Care in a Danish Hospital

This study aimed to investigate the organisation and evaluation of generalist palliative care in the hospital setting using three existing, independently collected data sources from a Danish hospital. These data sources came from three different datasets, all evaluating Standard 2.19.1 for general palliative care from the Danish Healthcare Quality Programme. As described in the methods sections the datasets were derived from:

1. A national survey
2. A national accreditation of the hospital
3. An internal self-evaluation performed in the hospital

These datasets were triangulated in order to identify concordances and/or discrepancies between them. A total of 56 sections from the hospital were included.

The results of this study showed that when the three datasets were compared, several discrepancies occurred with regard to the organisation, evaluation and performance of general palliative care. Five types of discrepancies on the fulfilment of the national accreditation standard for general palliative care were found in 35 out of 56 sections, representing 19 departments. The types of discrepancies were between the national survey, the international accreditation and the internal self-evaluation, but a discrepancy was also found internally in the self-evaluation, which created doubt on whether the standard had been effectively implemented.

Several disagreements in the responses from the hospital management and the department managements were found, and indicated that general palliative care is organised locally within the various departments and is practised without any overall structure or policy. The disagreements were both in accordance with questions on the policy for, and focus on, general palliative care; the

allocation of resources to general palliative care; instructions/guidelines for general palliative care; and the registration of general palliative care.

The triangulation of the datasets indicated a poor validity of the results from existing methods used to evaluate general palliative care in the hospital. Furthermore, the study advocates for more research on both the organisation of general palliative care and the indicators for high quality palliative care provided by the hospital. This lack of valid indicators also called for more qualitative insight in the clinical staff's daily work, including their culture and acceptance of the provision of general palliative care, which was the focus of Paper 2.

Paper 2: The Culture of General Palliative Nursing Care in Medical Departments - An Ethnographic Study

This study aimed to explore the culture of general palliative nursing care, focusing on the setting, the practice and the nurses' reflections of the care in medical departments.

An ethnographic study was undertaken, using James Spradley's 12-step method. A field study was conducted, which included observational field studies and interviews with nurses from three medical departments in a Danish regional hospital.

The findings were three cultural themes:

1. The cultural scene = general palliative nursing care in a treatment setting. This theme demonstrated that the care took place in a *fix-it* setting, characterised by a time-saving structure with emphasis on effectiveness and actions performed by *fix-it* nurses. This was a challenge in providing high-quality, general palliative nursing care.

2. Transition to loving care = licence to perform palliative care. Practice of general palliative nursing care. This theme showed that the general palliative care was practised according to a traditional care model, with a sharp division between curative and palliative care. There seemed to be a 'sluice gate' between treatment-related care and palliative care. This gate was opened by the decision to provide palliative care instead of active treatment – effectively ordering loving care, which allowed the provision of general palliative nursing care to commence. The term 'loving care' was used as a synonym for 'care of the dying', apparently without any expressed or shared content between the healthcare professionals.

3. *Potential for team improvement – reflections on general palliative nursing care.* In this theme knowledge and skills with regard to palliative care differed from nurse to nurse. The result of this was an individual and personally performed nursing care, and not ‘a joint effort’. This demonstrates a fragmented culture in which the quality of the general palliative care was at risk of being dependent on who was on guard. The individual nurse claimed that she did the best she could, but there was a demand for a better collegial palliative environment to develop the general palliative care nursing culture.

This paper finds that general palliative nursing care as a culture in the medical departments seems to be embedded in a setting that is not suited to palliative care. The care was still being practised according to the transition model of care, with a sharp division between disease-oriented treatment and palliative care. It was practised in a fragmented and individual way. The term *loving care* was used as a ‘gate-opener’ to provide palliative care for the dying but without the expression of any shared agreement on what that care involved.

The study concluded that individual and professional skills are not enough to improve general palliative nursing care in the hospital; leaders at all levels of the hospital’s organisation must prioritise this area as a focus of interest.

Since both Papers 1 and 2 found that palliative care was practised by local and individual forces, the organisational and cultural gaps in the organisation were explored through a mixed methods merging in Paper 3.

Paper 3: Generalist Palliative Care in Hospital – Cultural and Organisational Interactions. Results of a Mixed-Methods Study.

This study aimed to investigate the interactions between organisation and culture as conditions for integrated palliative care in hospital and, if possible, to suggest workable solutions for the provision of generalist palliative care in a hospital setting.

For this a convergent, parallel mixed-methods design was chosen and data from Papers 1 and 2 were compared, contrasted and interpreted using a comprehensive three-perspective analytical

framework of organisational culture with the concepts of integration, differentiation and fragmentation.

Two overall themes emerged from this comparison:

1. General palliative care as a priority at the hospital: This theme relates to contrasting issues regarding the prioritisation of palliative care at different organisational levels in the hospital. The general palliative care did not function according to an overall policy and the nurses did not regard palliative care as an effort prioritised by management. Concerns were expressed about lack of time and resources.

2. Knowledge and use of palliative care clinical guidelines: This theme relates to contrasting issues regarding knowledge and use of the existing palliative care clinical guidelines, which did not seem to have reached all levels of the organisation. The knowledge did not seem to have been conveyed beyond the level of departmental managers, since it was unfamiliar to the nurses working in the departments. Furthermore, the hospital management was unaware of its existence.

In both themes, organisational gaps were found between the levels of hospital management, departmental managements and the individual nurses.

This paper finds contrasting issues in the hospital's provision of general palliative care at different organisational levels, regarding both the prioritisation of palliative care, the policy of palliative care and issues regarding knowledge and use of the existing palliative care clinical guideline. This seems to hamper the interactions between organisation and culture – interactions which appear to be necessary for the provision of integrated palliative care in the hospital. Future workable solutions for practice must address and recognise palliative care as an important and legitimate task in all hospital departments, at all organisational levels. Palliative care must address a general approach in order to avoid the provision of palliative care as a self-composed/individual practice.

Chapter 4: Discussion

In this chapter the results and findings regarding the organisation, evaluation and culture of palliative care will be discussed across the three objectives. Furthermore, methodological considerations related to each phase in the thesis will be reflected on. The discussion will take place in the context of existing research and the theoretical inspiration. Firstly the organisation of general palliative care in the hospital will be addressed; secondly the evaluation of general palliative care; thirdly the culture of general palliative care; fourthly the methodological considerations as well as the researcher's role in mixed methods and finally workable solutions and implications for practice will be discussed.

Discussion of Results and Findings

The overall aim of the thesis was to explore the general palliative care in a hospital in order to suggest workable solutions for practice.

The work has covered several organisational levels, from an overall level to the work of the individual nurse in the medical department.

Figure 3 illustrates both the different levels and aims addressed throughout the thesis and the complexity in the field of palliative care in the hospital, since it is influenced by global, national and regional guidelines, as well as the policy at the hospital and by departmental managers, nurses and other healthcare professionals.

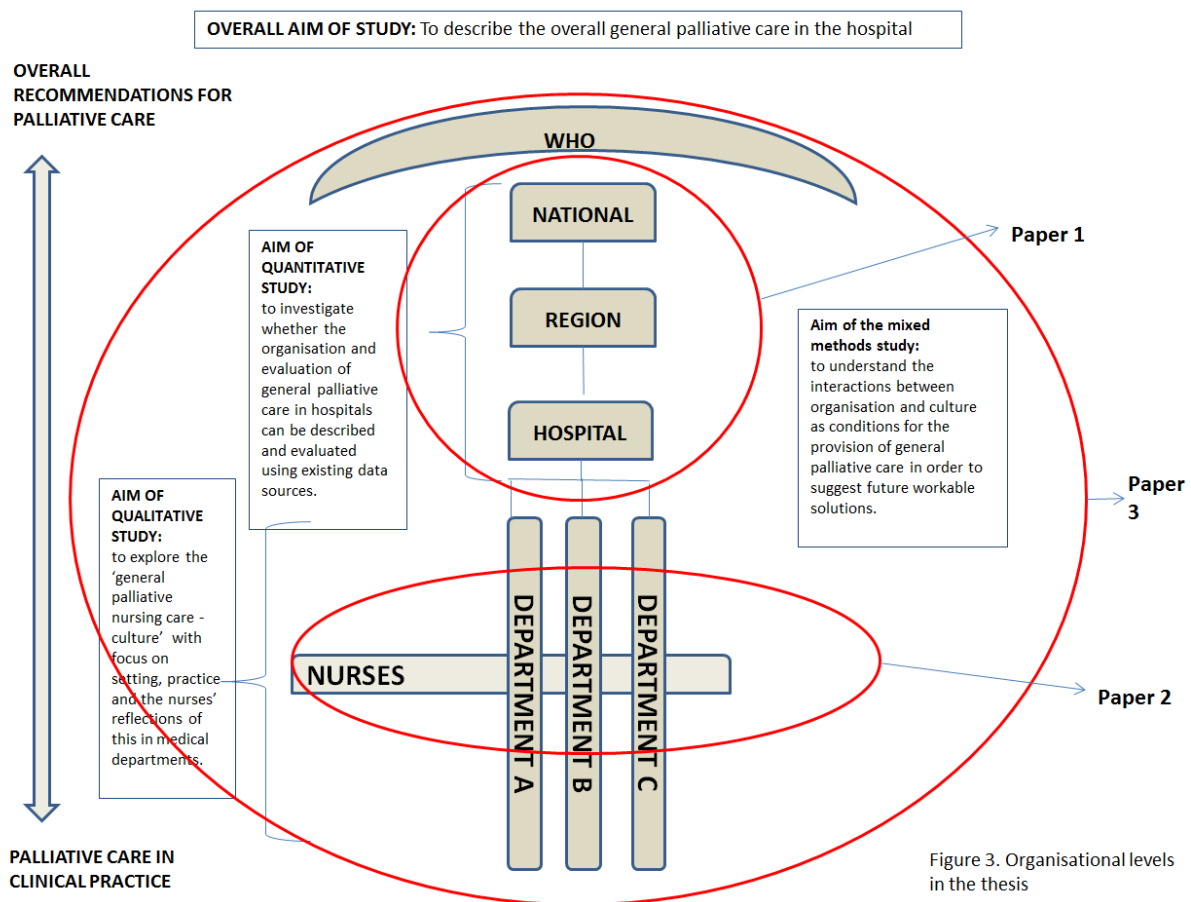


Figure 3. Organisational levels in the thesis

The Organisation of Generalist Palliative Care in the Hospital

By examining a national survey conducted by PAVI (Bergenholtz et al. 2015a; Jarlbaek and Timm 2015) as well as conducting an ethnographic study (Bergenholtz et al. 2015c) it has been possible to provide new knowledge regarding the organisational culture of the different levels in palliative care (here hospital management, departmental managements and the individual nurse) which to our knowledge has not been studied before.

The purpose of using a cultural organisational framework as theoretical inspiration was to discuss the interactions between organisation and culture as conditions for provision of palliative care, as well as illuminating the pitfalls between the different organisational levels in the hospital. By using Joanne Martin's framework (Martin 2002) of organisational culture, it has been possible to identify that there seems to be a consensus (*integration*) that the overall task at the hospital is disease-

oriented treatment. This is reflected in the organisation of care, the physical environment and in the nursing practice and resonates with existing studies (Chapple 2010; Dahlborg-Lyckhage and Liden 2010; Gardiner et al. 2011; Willard and Luker 2006), which all describe that competing interests in the hospital between disease-oriented treatment and palliative care are a challenge to the quality of care.

As described by the American researcher Helen Chapple (2010), dying in the hospital is influenced by the ideology of rescue, which influences the view of death in the hospital since this ideology is the most dominant. The results from this thesis illustrate an emphasis on curative/disease-oriented treatment, which gives the impression that palliative care is not prioritised in the departments. However, this conclusion should not be seen as an indication that there is no desire to prioritise palliative care, but rather that there is very little opportunity to prioritise it when the focus is on efficiency and disease-oriented treatment. The results in this thesis also showed that the competing interests between the palliative and disease-oriented care might result in palliative care being postponed until very late in an illness trajectory. The dominant medical discourse in the hospital, which regards death as something to be resisted, postponed or avoided, as described by Clark (2002), is also an explanation for late initiation. Even though this was seen to be a consequence it should be noted that the nurses in this study felt that the course of palliative care was initiated too late and were frustrated at not being able to relieve the patients' symptoms. So this consensus surrounding the dominant disease-oriented care exist side-by-side with frustrations and a wish to do better.

As also revealed in the quantitative study (Bergenholtz et al. 2015a), there is a general lack of resources specifically allocated to the provision of generalist palliative care. In the hospitals' reimbursement system there are no DRG-codes (Diagnosis Related Group) for general palliative care; only on the level of specialised palliative care is a DRG-code available. What can only be speculative, is whether this means that palliative care is not regarded as a part of the department's productivity and has to be delivered within the existing framework of the department's activities and budget? A study by Gott et al. (2012) highlights the problems which exist in the integration of palliative care into a generalist workload, due to the fact that palliative care was not seen to be combined easily with the disease-oriented tasks – however the palliative care was viewed as "part of everybody's job", making it a task that everybody should provide. It is evident that the requirement for general palliative care in the hospital cannot be met simply by introducing DRG-

codes so that the departments are remunerated for providing this service. There are multiple challenges. However, this study finds that the nurses' initiations of palliative care were triggered by the doctors opening the *sluice*. This finding paves the way for a discussion of whether DRG-codes could serve as an incitement for making palliative care a legitimate part of the tasks in a department.

Profound disagreements (*differentiation*) were found in the different levels of the organisation and the palliative care was far from being based on a systematic, overall general policy as suggested in the recommendations. Rather, the effort was found to be locally anchored. This thesis demonstrated that the differentiation created gaps between the different levels – hospital management, departmental managements and the individual nurses – which gave the impression that the palliative care practice was performed by several actors, with no overall policy and prioritisation. A lack of feedback between organisational levels in hospitals has also been demonstrated by Coustasse et al. (2007), who investigated the organisational culture in an American Hospital. Clearly this setting is not directly comparable to a Danish Hospital, but it might suggest that some organisational structures in the hospital setting create gaps which prevent a joint effort from taking place.

Furthermore, the results are supported by (Cassell et al. 2003) whose ethnographic study in critical care units showed that end-of-life care varies according to an administrative model, where the goal for the patient differs from doctor to doctor depending on their clinical background.

The lack of an overall policy might explain some of the challenges described in other studies, resulting in a lack of planning of palliative care (Bauman and Temel 2014; Dalgaard et al. 2010; Reyes-Ortiz et al. 2014; Temel et al. 2010; Thoonsen et al. 2011); a lack of consensus on the early initiation of palliative care (Murray et al. 2005); and a lack of communication and teamwork around the palliative care patients (Hamilton and McDowell 2004; Wallerstedt and Andershed 2007). To ensure that palliative care is a priority across the healthcare sector these challenges might be addressed by establishing an overall policy at all levels. However, as the fragmentation perspectives will show, this is not the only requirement.

From a *fragmentation* perspective (Martin 2002) palliative care was characterised as a self-composed and individual practice, which resulted in fluctuating and changeable care. Personal and emotional characteristics have earlier been described as influencing palliative care (Rhee et al. 2008) and nurses tend to have a sense of a good or bad death, in accordance with their own personal

values (Costello 2006). The ethnographic study in this thesis also found that none of the nurses rejected the importance of palliative care. They found it to be a core nursing task, which they valued and felt, should be prioritised. However, no initiatives or actions on this matter were seen – only a continuation of the clear prioritisation of fast and efficient treatment. From the fragmentation perspective defining the organisational culture is difficult since it is constituted by ambiguity and fragmentation. However, this ambiguity and fragmentation is an important part of the culture since it signals that palliative care is not a joint effort with an overall policy.

The culture seemed to be shaped by fragmented and individual opinions which were not shared among the healthcare professionals. This demonstrates that an overall policy is not the only solution to ensure an increased focus on palliative care. The palliative care must be clearly supported and prioritised by hospital managements, but at the same time initiatives must include and be sensitive to the perspectives of healthcare professionals, patients and relatives in a ‘top down – bottom up’ approach (Bate et al. 2004).

As this thesis has primarily taken an interest in describing the organisation on a micro-level (Alvesson and Kärreman 2011) it should be noted that the macro-level (international and national policy) influence the organisational culture in the hospital by creating the overall structural frameworks. This means that international and national level in theory influence the culture at stake in hospitals. In this thesis, recommendations at the international level (World Health Organization 2013; World Health Organization 2014), the European level (Radbruch and Payne 2010) and the national level (National Board of Health 2011) did not seem to have reached the organisational levels of palliative care at the micro-level and the care does not seem to be controlled by an overall policy. A study from the UK (Gott et al. 2013) likewise found significant gaps between national policy on the Gold Standard Framework regarding the transition for older people to palliative care and the actual practice, indicating that it is a common problem and not just applicable to a Danish Hospital.

The use of an organisational framework in this thesis has helped to allow a discussion of the palliative care in the hospital from different perspectives. The framework has worked as a support in the discussion of the results and has guided the discussion on how different views of the organisational culture can show that the practice of general palliative care is currently composed of a number of different viewpoints. However, using this framework does not cover all the layers that

exist in the organisational culture of palliative care in a medical department. Choosing another angle, for example the palliative culture of the doctors, might have shown different perspectives. Future research should address this in order to approach a more complete picture of general palliative care in hospital.

The Evaluation of General Palliative Care in the Hospital

The evaluation of general palliative care in the hospital made use of different methods. The evaluations all related to the fulfilment of the standard for palliative care as suggested in the DDKM accreditation programme (The Danish Institute for Quality and Accreditation in HealthCare (IKAS) 2009) and contributed with knowledge on the evaluation and usage of existing regional palliative guidelines. The findings from the ethnographic study also provided knowledge on the use of this guideline from the perspective of the individual nurse.

By comparing the different evaluations profound weaknesses were found in these existing evaluation methods for palliative care, due to several discrepancies and concluded that the evaluation made by the national accreditation programme was not suitable for evaluating the care. Separately the evaluations showed that the palliative care lived up to the standard that was expected. However, the comparison revealed several disagreements which might witness the invalidity of the individual evaluations. For example, the hospital management did not know of the regional palliative care guideline, whereas 45 % of the departmental managements responded that they used this guideline in their departments; and almost all the nurses had neither heard of nor used the guideline in their practice.

An older but well-known systematic review by Cabana et al. (1999) showed that barriers in the use of clinical guidelines have generally been related to knowledge (lack of knowledge of guidelines), attitudes (lack of agreement) and behaviour (lack of time or other external factors). This results from this thesis suggests that the lack of knowledge is the most prominent, since guidelines do exist. What is missing is the awareness of these guidelines, since there is nothing to indicate that there is a lack of agreement with the existing guidelines.

The evaluation of palliative care has been internationally shown to be difficult, because of a lack of suitable quality indicators. A systematic review by Pasman et al. (2009) shows that there is a large number of quality indicators, but these have not been described in detail and there is a need for

methodological specification in order to assess and monitor the quality of palliative care. As efforts are being made in developing quality indicators applicable to all palliative care settings (Leemans et al. 2013), including diagnoses other than cancer (van Riet et al. 2014), our study emphasises that the process of creating awareness/knowledge of these is also of high importance.

As the aim of the standards in the DDKM accreditation programme is to improve the quality of the services provided by the hospital, it must be questioned whether this is achievable when one looks at the results from the quantitative study, which indicate that it is not possible to evaluate the palliative care from the methods currently in use.¹

Furthermore, as shown by Ahmed et al. (2014), at the present moment there is no systematic, holistic approach for screening patients for palliative care needs. But since it is seen that the implementation of palliative care programmes improves the quality of life for patients with advanced, chronic illnesses (Meier 2005) it is recommendable to further develop systematic tools for general palliative care.

Raising the awareness of palliative care needs may help the professionals, as well as the patients and their carers, in relieving symptoms (Murray et al. 2005; Temel et al. 2010), especially in an early targeted way (Dalgaard et al. 2010; Dalgaard et al. 2014; Temel et al. 2010). A European white paper was recently drafted to define optimal palliative care for elderly people with dementia (van der Steen et al. 2014). This suggests that there is a realisation that categories of patients other than those suffering from cancer can also benefit from palliative care. However, results and findings in this thesis indicate that this awareness in the medical departments is still at an early stage. As mentioned in the background section, the patient in need of palliative care is defined as the patient with a life-threatening disease (including diseases other than cancer). Identifying these patients is a challenge, especially for those not suffering from cancer. This was also seen during the observational study in this thesis, where the term *life-threatening disease* did not seem to have been integrated into daily practice in the medical departments, which might “leave it up to” the individual healthcare professional to identify the palliative care patient and initiate palliative care.

¹ It should be noted that a political decision was recently made to phase out the current DDKM programme and to set broad national goals, which the individual hospitals have to adhere to by self-governance. The aim of this is to simplify the quality assurance work in the hospitals (Larsen 2015).

It should be problematised whether it makes sense for the healthcare professionals to work from the broad definitions suggested by WHO and the national recommendations (patients with life-threatening diseases) (National Board of Health 2011; World Health Organization 2014). These definitions were created to draw attention to the fact that patients other than those with cancer can have palliative care needs, but the term *life-threatening* does not seem to have been implemented in a daily practice in medical departments.

The Culture of General Palliative Nursing Care in the Hospital

As mentioned earlier, in the background chapter, existing studies have described numerous challenges relating to palliative nursing care in hospital, indicating that the hospital is a less than ideal setting for the dying patient and leading to frustrations among the nurses.

The ethnographic study in this thesis found that general palliative nursing care culture was found to take place in a *fix-it* setting characterised by a time-saving structure with emphasis on effectiveness and actions provided by *fix-it* nurses, leaving little room for the palliative care. This resonated with previous studies (Ferrand et al. 2008; McDonnell et al. 2002), which likewise found that the hospital was not seen as an ideal setting for dying patients. When the primary task in the departments is considered to be the 'treatment' of diseases, it is difficult to provide concurrent, high-quality palliative nursing care (Gardiner et al. 2011; Willard and Luker 2006).

In the ethnographic study the physical environment of the hospital was found to be of importance since this reflected that the medical departments were not 'geared up' for palliative care. The aesthetics were not taken into consideration, but signalled a focus on practical and effective treatment. The importance of an aesthetic environment for the well-being and interpersonal interaction for seriously ill patients has been described in other studies done on the oncology wards (Larsen et al. 2013; Timmermann et al. 2014). From the results of the present study it can be argued that this is also applicable to other hospital wards.

As described by Thompson et al. in 2006a, nurses have reported that they believe the physical surroundings affect the quality of care for the dying patients, and that strategies for changing these surroundings should be optimised. Furthermore the physical environment should be used as a therapeutic part of the nursing care (Edvardsson et al. 2006). The nurses in the ethnographic study in this thesis did not reflect on the physical environment until death was imminent and "loving care"

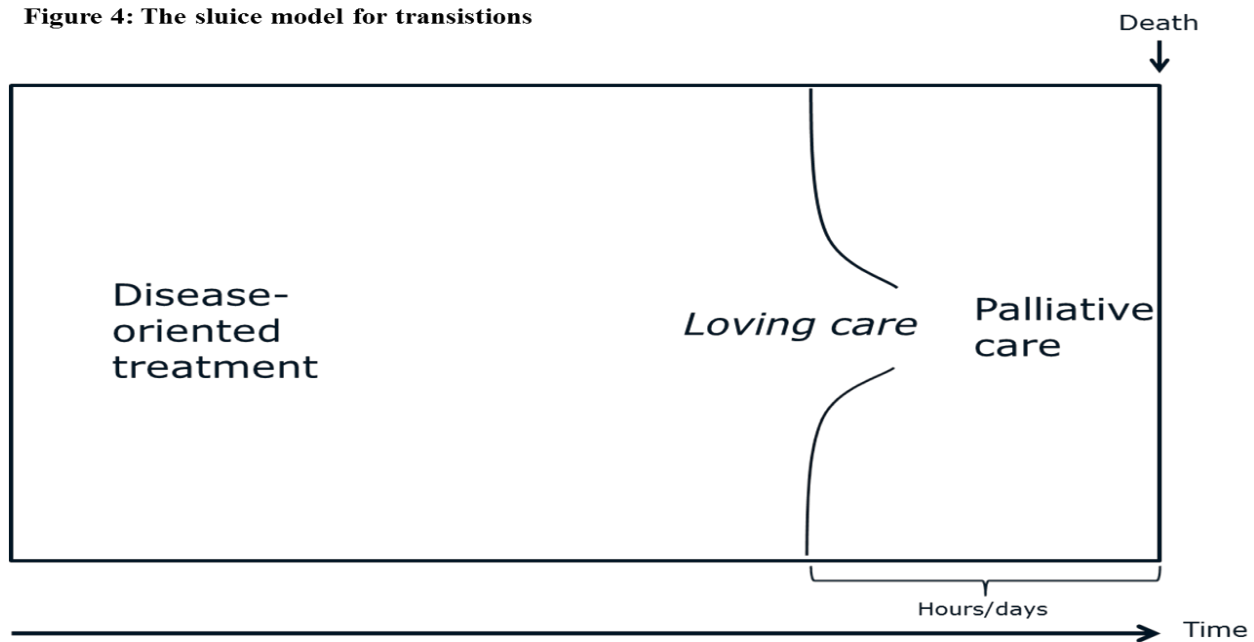
was ordered. Only then did they reflect on the environment and tried to shield the patient and make room for relatives to stay.

The ethnographic study in this thesis found that the culture of palliative nursing care was embedded in the old transition model of care presented by (Lynn and Adamsson 2003), where palliative care was not initiated until death was imminent. This supports previous findings which demonstrates the lack of timely initiation of palliative care (Dalgaard et al. 2010; Davidson et al. 2002; Gott et al. 2011; Wotton et al. 2005). Guidelines recommend the use of a trajectory model, where palliative care can ideally be part of the illness trajectory from beginning to end (Lynn and Adamsson 2003), and should be implemented in trajectory models (Murray et al. 2005) demonstrating different patterns of decline in various diseases. However, in a Danish study by Nielsen and Raunkiær (2014) the unpredictability associated with other diseases has been shown to paralyse the initiation of palliative care. In the ethnographic study in this thesis nurses often felt that palliative care should be initiated at an earlier stage, and they found palliative care relevant for patients with chronic diseases. Difficulties and frustrations related to the identification and symptom relief for chronically ill patients was expressed by the nurses during the interviews.

However, despite this awareness, the trajectory model (which is diagnosis-dependent) was not implemented in practice. Rather, palliative care was seen as a practice resembling the transition model of care. When the patient's death was imminent, the doctors prescribed "loving care" – and this was like opening a sluice gate for the nurses to provide palliative care (Bergenholtz et al. 2015c).

Figure 4 illustrates how the transition was observed to take place:

Figure 4: The sluice model for transistions



When this sluice gate was opened (by the doctor articulating and prescribing loving care) the nurses stated during the interviews that they felt it legitimised them spending time with the dying patients and relatives. However, the observational study did not confirm this prioritisation, as only a very small amount of time was spent in the room with the dying patient, and was always related to specific tasks, such as medication. This has also been described by Costello (2001) claiming that nursing care for dying patients is primarily aimed at meeting patients' physical needs. A recent Danish study has described general palliative care for cancer patients as “disheartening” as its focus was restricted to identifying physical and emotional problems (Soelver et al. 2014).

Saunders also used the term “loving care” but she expanded it to “efficient loving care”, which she considered to be an aim for the care of the dying. She claimed that all resources must be exploited to achieve this (Saunders 2006 p. 152). The adjective *efficient* means that it is an active type of care, rather than a passive one. In our study “loving care” seemed to conform only to the individual health care professional’s personal definition, which means that we cannot know how efficient its practice is, what professional qualities are associated with the term, or how the term *loving* is expressed.

The concept of *love* in nursing has been explored by Fitzgerald and van Hooft (2000), who find that even though this has not been clearly defined, it is concerned with going beyond the call of duty in care; there is a dimension of commitment and dedication, which can put the nurse’s own wellbeing

at risk. As described by Arman and Rehnsfeldt in 2006, love in nursing does not arise from acquiring new knowledge but is an expression of loving presence in the nursing care.

In the ideal of providing “a good death” for a patient there is also the will to go beyond oneself and to fulfill the desires he/she might have and in this sense give “loving care” to the patients. In the observational study, in this thesis, the concept of love was not expressed other than when the nurses referred to loving care which was synonymous with terminal palliative care. Even though the word “love” was not defined it was clear that the nurses had a wish to provide the best care for the patients and relatives, going beyond their usual care practices. When asked to identify what they did differently for these patients they described a want to do something “extra” for the patients in need of palliative care, such as cuddling their feet, stroking their cheeks and staying on duty for longer, which could be a sign that nurses are putting themselves on the line in their provision of loving care.

The nurse’s role in initiating palliative care actions seemed to be rather passive and anticipatory of the doctor opening the sluice for palliative care. This passivity in nursing is also described by Bloomer et al. (2013b), who likewise found that nurses did not recognise the dying and continued to provide active care until a doctor declared that the patient was dying. Even though, in our study, the nurses were in agreement that palliative care was initiated far too late no action to start palliative care was taken until there was a clear order for loving care by the doctor.

As proposed in the background chapter there appears to be a culture in the hospital which is in opposition to the palliative philosophy which also described by in an ethnographic study from a medical department in Canada (Chan 2014). Chan describes the conflict between two approaches (the curative and the palliative) with regard to care for the dying patient. The curative approach is prioritised in the care for dying patients (ibid.) which creates a “clash” between the two approaches. The culture of biomedicine, is in opposition to the palliative philosophy because of the clash between reductionism and holism (Chan et al. 2009) which this thesis demonstrates as well. Furthermore, this thesis found that existing culture leave very little room and attention to palliative care.

It is important to note that the culture is also shaped by the conditions in the organisation under which the nurses are required to practise. At no point did the study see any resistance to providing

palliative care or a denial of the importance of this task. All nurses perceived palliative care as a core nursing task.

Nursing in Denmark has been described as a profession which is under pressure due to extensive changes and cuts. A report including 3,496 nurses in Denmark, published in 2013 by the Danish Nursing Organisation (Dansk Sygeplejeråd) (Kristensen 2013), shows that the nurses' working environment is characterised by a heavy workload, high tempo and emotional demands, especially in acute care settings. Due to this it should be problematised whether nursing in general can be practised as holistic given the conditions described above. The observational study in this thesis study found that there was a clear demand for effectiveness and action, which appeared to be a parameter of success for nursing. But although the field of nursing is under pressure, the report by the Danish Nursing Organisation also showed that more than 90% of the nurses defined their job and their own input as important (ibid.), which suggests that great pride is taken in the profession; this was also seen in the observational study from this thesis, where great pride was taken in providing palliative care in the best possible way.

Methodological Considerations

In this section the validity, reliability, rigour and challenges of the three studies will be discussed.

Quantitative Phase: Limitations, Validity and Reliability

The survey and self-evaluations proved to be unsuitable and unreliable for the investigation of the organisation and evaluation of general palliative care in the hospital (Paper 1).

The weakness of the study is the lack of knowledge of the considerations that lay behind the responses, and due to the retrospective design it was not possible to influence the content of the questions for the purposes of the study, nor the persons questioned.

Since two of the three evaluations of the general palliative care were based on self-reporting it should be emphasised that a tendency to over-estimate adherence to guidelines in self-reported situations has been demonstrated by (Adams et al. 1999). Self-reporting should therefore not be the only method used to evaluate clinical practice. However, the use of three different datasets addressed this challenge and gave the opportunity to approach this issue and to question the validity of the evaluation procedure.

The discrepancies demonstrated in quantitative results 1 indicate that both the validity and reliability of the individual methods for evaluation of general palliative care are poor. This discussion is further addressed in Paper 1 (Bergenholtz et al. 2015a).

Furthermore, it should be noted that the three studies in Paper 1 had different aims, which is a concern since the datasets were not designed for this kind of comparison. It can also be questioned to what extent generalisations can be made, since the sample came from only one hospital in Denmark. However, the hospital was a large regional hospital, whose organisation and administration are similar to other Danish hospitals of similar size. When results from the case hospital were compared with the responses reported in the national PAVI-study (Jarlbaek and Timm 2015), the hospital appeared to be representative of Danish hospitals in general.

Qualitative Phase: Rigour

Several terms exist to describe the rigour of the qualitative data (Creswell 2013), but in this study the methodological rigour was assessed using Malterud's terms of relevance, validity and reflexivity (Malterud 2008; Malterud 2001).

Relevance: Relevance was attempted by covering the literature on general palliative nursing care prior to the study. This was done to ensure that the topic was relevant to the field of palliative nursing care.

Also feedback from the participating departments and nursing staff was an integrated part of the field study (Spradley 1980) and the participants clearly stated that they perceived the research topic as highly relevant. It should be noted that there was a very positive atmosphere among the staff when I (the candidate) was there and everybody welcomed the topic. This indicated that the participants recognised the relevance of the research topic.

Validity: Since it is not the aim of qualitative research to produce repeatability, but to describe unique and detailed descriptions of the diversity that a given phenomenon can provide (Brinkmann et al. 2010; Malterud 2008), internal and external validity was achieved by allowing the readers to judge transferability by detailed views, quotes and field notes. These are presented in Paper 2.

In order to validate the actors' point of view (and not solely the interpretation made by the researchers) (Spradley 1979; Spradley 1980) I presented the findings/themes in each department to a group of nurses during a morning meeting (approximately 45 minutes). This was done to determine whether the themes met recognition or resistance in the actors. In all three departments there was a high degree of recognition and there were no comments from the staff who disagreed with the themes. On the contrary, the nurses explored the themes in greater depth and verified them through reflection.

Reflexivity: An important part of doing qualitative research is the ability to be reflexive about the subject studied and to realise that the researcher may be influencing what is observed, as well as the analysis; this is because, - the researcher is also the research instrument, which could be characterised as a bias (Malterud 2008; Malterud 2001). As described by Hammersley and Atkinson (1995), the qualitative researcher is an active respondent (an instrument), in which identities of researcher and human-being are intertwined. As part of this study, reflexivity was achieved by keeping a reflective diary (Ortlipp 2008). This diary contained reflections, feelings and experiences of situations related both directly to the observational study and to events in my personal life.

Doing qualitative research in palliative care can create difficult situations, where the role between being a nurse and a researcher may conflict (Dean and McClement 2002). In the dichotomy between being an insider-outsider in qualitative research there is a space (Dwyer and Buckle 2009). This space was, in this study, created by on the one hand I was a researcher with a nursing background, which meant that I was recognised by other nurses as being an insider; simultaneously, I was an outsider in the departments. The position of an insider made it easier for me to understand the context of the research (understanding the medical terms, knowing some of the routines and how the hospital as an organisation works) and was clearly a door-opener for me among the participating nurses. Although some scepticism arose when the nurses found an "outsider" in their department, this quickly turned into optimism when I told them that I was also a nurse. The position of an outsider made it possible for me to observe what was going on without being a part of the daily routines.

However, the most personal challenging during the fieldwork for me was combining the position as a researcher with the position as a nurse. Even though it was not an ambition to stay objective, but merely distant to the observed, it was sometimes very difficult. I was not fully in the role of nurse at

any time, but in some situations I assisted the other nurses by, for example, helping to bring food to the patients or getting them out of bed. However, some situations with blurred role boundaries, as described by Bloomer et al. (2013a), occurred in relation to my profession as a nurse. For example, in one of the departments the doctors were very interested in learning more about palliative care and thought that I was a specialist in this area. This led to the doctors sometimes consulting me by asking questions such as: *“What do you think we should do in this situation?”* I found this challenging, but I politely explained that my role and mission in the department was that of a researcher and not a palliative expert.

The most difficult situations for me were those in which I observed actions which were in conflict with what I, as a nurse, would have done. An example of this can be found in the field notes, where I participated in the daily round, visiting a dying patient with the nurse and a doctor. The topic is whether this patient (who was dying) should have a gastric feeding tube, allowing her a chance to live a little longer:

“There is a woman with an oxygen supply in a two-bed ward, sleeping soundly. She is red in the face. Large the doctor leans over her in the bed and begins to talk loudly. She wakes up. Says a few words. I don’t think she understands what the doctor is saying. Her breathing is laboured and it sounds as though there is a lot of mucous in her lungs. She appears to be dying. I think it would be too invasive for me to insert a gastric tube. As a nurse I would not be able to do this for ethical reasons.

She’s lying uncomfortably in the bed. Dry lips. Anguished. She thinks my hands are very cold, when I spontaneously take her hand in mine. She doesn’t like it. I think she is in so much pain that every touch is painful to her. I apologise for my cold hands and withdraw them.

The doctor tells her about his plan to introduce a gastric tube. No matter where he touches her it hurts. Pain in her feet, hands, everywhere. I think he registers it, but he only prescribes paracetamol for pain relief.

The plan for the gastric tube goes ahead. The nurse doesn’t do anything but makes a note about it in the papers.

That day it hurts when I leave, because of not being able to do anything, since I am now in my researcher role. It hurts to see her suffering and not help her.”

I tried not to interfere in these situations, but I was morally challenged by this and left with a feeling of “not doing anything”.

The situations were discussed thoroughly between me and my principal supervisor during the ethnographic analysis, both in order to expose my preconceptions and blind spots and to develop my skills as a qualitative researcher. As I was new to the area of observational studies, this development was necessary and useful.

As described in Paper 2 (Bergenholtz et al. 2015c), there were only a few observations with dying patients in the observational study. This could be seen as affecting the quality of data to the extent that the variety of situations and the saturation of data are inadequate. However, as argued by Guest et al. (2006), the sample size in qualitative research is very difficult to estimate due to variations in the saturation. Malterud et al. (2015) suggests in a recent publication that sample size should be guided by “information power” which makes the sample adequacy, data quality and variability of events more important than the actual size of participants or events.

The aim of the observational study in this thesis was to describe the uniqueness in the situations and not to generalise the findings. However, it should be noted that the nurses in the individual and focus-group interviews shared many stories about the practice of handling dying patients and these stories were also included in the analysis and informed the results. Furthermore, the observations were not only in relation to dying patients but also to patients with life-threatening diseases – and there were many of these in the departments. In department B, all patients could be characterised as having life-threatening diseases, as they would die without the treatment they received in the clinic, even though this was not the nurses’ definition.

Furthermore it is important to state that the findings from this study are affected by the researcher (the candidate) and my preconceptions, which can only provide a picture of a given moment and place. It is possible that my presence may have affected the nurses’ actions. However, the observations were repeated for two weeks in each department, which may have minimised this possibility. Furthermore, the possibility exist that another researcher, at another given time and place, may have generated other findings. This study has tried to achieve rigour by reflecting on relevance, validity and reflexivity, as suggested by Malterud (2001).

Mixed Method Phase: Validity and Challenges in Mixed Method

Since the qualitative and the quantitative methods stem from different ontological and epistemological assumptions, challenges in the mixing are unavoidable.

In both the qualitative and the quantitative paradigms strengths and weaknesses have been described, and the aim of the mixed-methods approach is to minimise these and find workable solutions. While the quantitative researchers argue from the positivist paradigm that all science should be objective and free of context, qualitative researchers from the constructivist paradigm oppose this notion and argue that there are multiple realities, which can only exist for the subjective knower (Johnson and Onwuegbuzie 2004).

The aim of mixed methods is not to choose between or replace either of these paradigms, but rather to strengthen them by eliminating their individual limitations. This is not done without difficulty, as will be described below. The most dominant weaknesses in the pragmatic paradigm relate to a failure in the knowledge of multiple methods and an understanding of how to mix them appropriately and create meaningful conclusions (ibid.). As mentioned in the methods section in the development of mixed methods, it has also been attempted to address the concerns which are raised in mixed-methods research. These concerns have been presented by Creswell as 11 controversies, ranging from defining mixed methods to how the paradigms can be mixed (Creswell and Clark 2011). It is controversial whether a mixed method gives the post positivisms an advantage and whether pragmatism is a paradigm of its own or merely an ideological position. Hereby the notion of mixed methods as a third research paradigm has been questioned. Giddings and Grant (2007) argue that mixed methods is a “Trojan Horse” for positivism, since they see the use of mixed-methods research as “...*through inclusion—neutralizing the oppositional potential of other paradigms and methodologies that more commonly use qualitative methods*” (Giddings and Grant 2007 p.59).

In other words, it is believed that the methodology in the qualitative methods is being undermined by the positivistic approach in mixed methods. Following on in the same critical vein, Denzin (2012) claims that pragmatism is used by many as “what works” without addressing the fundamental differences in post positivism and constructivism. However, there is a rigour embedded in the pragmatic approach in mixed methods and the search for workable and applicable solutions, which takes into account the various paradigmatic approaches in order to claim validity.

In this thesis I try to overcome this issue by clearly addressing problems of validity in mixed methods. These problems have been identified to cover both the data collection, data analysis and the interpretation process (Creswell and Clark 2011). In this thesis both the data collection and analysis the paradigms were kept separate. The merging of data took place after this, giving an opportunity to identify the validity and rigour of the individual studies in order to spot possible problems for the mixed methods merging. The obvious challenge was the fact that the separate studies addressed different research questions, which made interpretation difficult. However, a mixed-methods approach in describing the field of general palliative care has been shown to be useful, especially in order to identify gaps and inconsistencies between the different organisational levels in the hospital.

It is important to consider the quality criteria for mixed-methods research. As described by Polit and Beck (2012), a discussion of the validity and trustworthiness of the individual studies, as well as the mixed methods terms *interference quality* and *interference transferability* (Polit and Beck 2012; Teddlie and Tashakkori 2009), is important – but often neglected. As validity and rigour have been described above, only the mixed- methods terms will be discussed in the following, acknowledging that the validity of the individual studies affects the mixed methods validity as well.

Interference quality is an overall term for evaluation of the quality of conclusions derived from the mixed-methods research. This is also what is called internal validity in quantitative studies and transferability in qualitative studies. In mixed methods it refers to the believability and accuracy of the mixed- methods conclusions (Polit and Beck 2012).

This thesis attempts to present the quantitative, qualitative and merged mixed- methods phases as transparently and rigorously as possible, allowing the reader to evaluate the process. It was clear that the mixed-methods process involved a considerable data reduction, and only the comparable themes were merged. This means that only a small fraction of a large amount of material has served as the subject for the mixed methods merging. The conclusions must therefore be seen as a narrow section of a large amount of material. A challenge also described by Creswell and Clark (2011) as the unintentional “danger” of giving more weight to one of the datasets than the other. To minimise this issue each research objective in the parallel phases was addressed separately, presented in Papers 1 and 2 and given equal attention in the merging of the results and findings. However, it is

clear that the extent of the qualitative work, when documented, is much greater, given the nature of qualitative research.

Interference transferability is a term for the degree of transferability of conclusions to other settings and contexts, also known as external validity in quantitative research, and transferability in qualitative research (Malterud 2008; Malterud 2001). The themes derived from this thesis only relate to one large regional hospital in Denmark. In the themes of prioritisation, knowledge and use of palliative guidelines, the results can only be validated as applying to this single hospital. As no other study, to our knowledge, has focused on the interaction between organisation and culture in general palliative care in hospital it is not possible to show a consistency with previous findings in order to achieve interference quality. However, what is already known is that internationally there are considerable variations in palliative care practices in hospitals (DeCato et al. 2013; Pantilat et al. 2012; Wennberg et al. 2004), which might indicate that the conclusions from this study might also apply in other hospitals. This study adds to the knowledge that not only is variations in the practice of palliative care in hospital, but also within each department and between individual nurses.

In order to assess the quality of the conclusion from mixed-methods research, guidelines and frameworks has also been proposed (Creswell and Clark 2011; Polit and Beck 2012; Teddlie and Tashakkori 2009). In mixed methods especially the criteria of whether the interpretations are more credible than other possible interpretations (Polit and Beck 2012), should be highlighted. This criterion can be understood as the question of what the study might have contributed with, if only one of the approaches (the qualitative or quantitative) had been used to address the overall research topic. Using a convergent parallel design this is addressed clearly by having two parallel phases with separate data collection and analysis, which makes it transparent for the reader to perceive what the individual studies contribute. The merging of these gives the study more breadth, since more aspects can be illuminated and more pitfalls were identified than the individual studies could do standing alone. The merging of the two phases shows that there is a lack of policy and organisation of palliative care across all levels, from the hospital management to the individual nurse, and suggests that future workable solutions must acknowledge these barriers within the organisation and the culture of palliative care at the hospital. The merged results increased the knowledge of the culture and organisation of palliative care in the hospital more than a single approach would have done.

- *The Researcher's Role in Mixed Methods*

Another aspect which should be addressed in the discussion on using a mixed-methods approach is the challenge which occurs in relation to the researcher's role in a mixed-methods study. It has been described that having the knowledge and competencies to master qualitative and quantitative methodologies, as well as having sufficient time for these in the study, is a core issue and challenge (Creswell and Clark 2011). The fact that one has to move from an objective and neutral position to a subjective, involved position in which one uses oneself as an instrument is difficult. The supervisor's competencies in each method, as well as in mixed methods, are of great importance and should be acknowledged. Doing a mixed- methods study as a PhD project has been shown to be achievable in this thesis, but reflections on what is not achieved are also important. The experience derived from this thesis is that mastering quantitative, qualitative and mixed methods merging skills as a single researcher is difficult and demanding. Mixed methods should preferably be done by a team of researchers, who can offer multiple competencies, with a mutual respect for each other's competencies and work.

However, in hindsight, given the complexity and nature of palliative care in organisations, a mixed-methods approach is still viewed as an appropriate choice for this study. The different perspectives explored the palliative care at the hospital from different angles and aimed to provide a broad overview of the palliative care, while making an in-depth study of nursing in the medical departments. This gives a picture of the different levels in palliative care, but there is a lack of further research into the various sub-cultures which exist and have an impact on the care. This study has only touched the surface of the collaboration between nurses and doctors in palliative care; this needs to be explored further, since it seems to be of great importance in initiating the care. The use of mixed methods in this study has provided some valuable pointers for further research.

Part of the rationale of using a pragmatic approach in research is to find a middle ground between the different philosophical paradigms in order to find workable solutions (Creswell and Clark 2011;Johnson and Onwuegbuzie 2004). These solutions will be discussed in the following section.

Workable Solutions – Implications for Practice

Based on the results and findings of this thesis it is not possible to present clear workable solutions, since profound gaps, disagreements and discrepancies have been identified in the organisational culture of palliative care. Rather, the thesis suggests that future work on general palliative care should address cultural and organisational changes in the hospital.

Organisational change is a difficult and highly complex issue, involving several steps and a long time-frame (Alvesson and Svenningsson 2008). Attention needs to be paid to the grand level, as well as the local level, including aspects of integration, differentiation and fragmentation (Martin 2002). The results and findings in this thesis should be seen as a contribution towards organisational change, since they provide knowledge about the understanding of the organisational culture in general palliative care as it exists at this given moment. The next step for organisational change is for the organisation to state where it wants to go and to devise a strategy for this change. Based on the results in this thesis, this should include strategies for how to make the hospital a better setting for patients with palliative care needs, as well as to identify these patients and further develop care towards the trajectory model of care (Lynn and Adamsson 2003). To achieve a successful introduction of integrated palliative care at an earlier stage in the patients' trajectories, there is a need for more awareness with regard to creating a common goal for palliative care at all levels in the institution. This can be achieved by using a 'top down – bottom up' approach, as described by Bate et al. (2004). Initiatives which create this awareness must be clearly supported and prioritised by hospital managements, but at the same time they must be sensitive to the context and to healthcare professionals', patients' and relatives' perspectives.

Another change should also involve suitable methods for evaluation, since current methods for evaluation proved insufficient. As the development of suitable quality indicators progresses internationally, tools for implementing these are also necessary.

Based on this thesis combined with existing knowledge, it will now be suggested which initiatives (workable solutions) could help to ensure that general palliative care becomes a widespread, well-structured and systematic professional practice in hospitals, making it an integrated part of the tasks and offering it to all patients with life-threatening diseases:

- An acknowledgement at all organisational levels in the hospital of general palliative care as an integrated core task, which should be provided alongside disease-oriented treatment
- Financial and administrative structures should be designed in order to leave enough time and resources for the integration of general palliative care in the hospital
- Improve the healthcare professionals' knowledge of existing guidelines and recommendations and develop context-sensitive strategies for the implementation of clinical guidelines on general palliative care
- Development of a systematic and holistic instrument for screening patients for palliative care needs for timely identification
- Initiation of both national and local plans for increased knowledge among healthcare professionals working in general palliative care.

It is important to note that these initiatives cannot ensure the achievement of a good death. As mentioned in the Background chapter, the good death is based on personal definitions, and can be difficult to achieve due to a lack of control over the dying process (Dalgaard 2010). It is not possible to ensure that everyone will have a good death by implementing the above workable solutions; however, it might be possible to overcome some of the barriers described by healthcare professionals, such as time constraints and staffing patterns (Beckstrand et al. 2006).

Despite efforts towards making palliative care a systematic and integrated part of the tasks in hospital, the individual experiences of patients and relatives will always be the prime indicator of whether or not a good death has been achieved. Furthermore, the suggestion of a systematic and well-structured approach does not mean that individually-tailored care and treatment should be replaced with a streamlined, rigid approach. It is important that the solutions are context sensitive as well as appropriate for the individual patient.

This thesis has provided insights in the practice of general palliative care in Denmark from a cultural organisational perspective. Palliative care is a field in rapid development, where changes in the culture and the organisation take place over time. In Denmark, palliative care is still in its early stages of development, whereas there is a more established tradition in the UK and the US. We are in the middle of a process of development, so we need to acknowledge that the culture of general palliative care and its underlying structures need time to evolve to maturity. However, the results and findings of this thesis indicate the need for a change of attitude such that the practice of general

palliative care in hospital becomes a legitimate part of the services provided, and the concept of palliative care extends beyond a specialised service for cancer patients in the terminal stage of disease.

Chapter 5: Conclusion and Perspectives for Further Research

The overall aim of the thesis was to describe the general palliative care in the hospital. This was done by addressing three objectives using mixed methods. The objectives explored the organisation, evaluation and nursing related to palliative care as well as the complexity within the organisational culture in order to suggest relevant interventions for practice. The main results and findings from the studies can be summarised as follows.

A mixed- methods approach, describing the field of general palliative care and ranging from a view of the overall hospital to the individual nurse, has been shown to be useful in identifying gaps and inconsistencies between the different organisational levels in the hospital.

This thesis suggests that the culture and organisation of palliative care are characterised by a lack of an overall policy and of goals for care. Palliative care is hampered by the hospital's focus on disease-oriented treatment, which is reflected in both the physical environment of the hospital, the organisation of care and in the care provided by nurses. Not only did variations in the practice of palliative care exist at the hospital, but they also existed within each department.

Despite national and international recommendations for an integrated trajectory model which integrates disease-oriented and palliative care, this study indicated that palliative care was practised according to the traditional model of transition, which distinguishes sharply between disease-oriented/curative treatment and palliative care. Access to palliative care was seen to be initiated by the ordination of "loving care", which was a term used without any clear definition among the healthcare professionals involved.

The demonstrated lack of focus and knowledge regarding existing recommendations among nurses in the medical departments resulted in non-systematic, individualised and fragmented care.

The lack of early initiation of palliative care, as well as difficulties in relieving symptoms for non-cancer patients, indicates that palliative care has not yet reached its target group according to the WHO's definition.

Furthermore numerous discrepancies were found regarding the fulfilment of the national accreditation standard for palliative care. This indicates that existing evaluation methods are insufficient. Each method showed a hospital that lived up to the requirements, but when the methods were compared inconsistencies were revealed, casting doubt on the degree of implementation of the standard. Based on this study, it seems apparent that the quality of palliative care provided by hospitals cannot be certified by performing the national accreditation procedure alone.

This study has only touched on the tip of the iceberg regarding an understanding of the complexity and handling of general palliative care in specific contexts in hospital. To fully understand this complexity further research is needed in several areas:

- Research that includes patients' and relatives' perspectives of their needs in palliative care trajectories in order to capture the actual experience of being a palliative and/or dying patient in a general setting in the hospital.
- Research which can strengthen the collaboration between nurses and doctors in generalist palliative care, since this is of great importance in initiating the care.
- Acknowledging that palliative care is an interdisciplinary approach. The present study has only addressed the culture and practice of nurses in medical departments. Studies are needed which include other healthcare professionals in hospitals and in other settings, such as home care and general practice. These could provide knowledge regarding the individual subcultures which exist in and outside the hospital, thereby illuminating possibilities and challenges with regard to organisational change and better continuity for the patient.
- A further exploration of the term "loving care" in order to better understand the concept and its professional content and to improve its efficiency.
- Finally, research is needed regarding how indicators can be established at hospitals for high quality palliative care for both cancer and non-cancer patients.

Not only is research needed in the area of palliative care in the hospital, but organisational changes are also needed. These changes should overcome the lack of an overall hospital policy, which at the moment seems to result in unstructured and personalised care in the departments.

Palliative care in the hospital is not a new topic: the management of the dying and the ensuring of a good death in hospital have been of concern in the US since the 1960s. Even though many initiatives have been seen since Glaser and Strauss emphasised in 1960 that work patterns in the hospital are out of step with the process of dying, palliative care in hospital still seems to be a challenging issue and is in opposition to the disease-treatment paradigm.

In 2014 professor Helle Timm stated: “*the story on palliative care in Denmark – is yet to be written*” (Timm 2014). The work presented in this thesis can be regarded as a step in this direction.

Summary

The overall aim of the thesis was to explore the general palliative care in a hospital in Denmark. This was attempted by describing the evaluation, organisation, practice and culture of general palliative nursing care, in order to propose workable solutions for developing palliative care.

Public debate and previous research have depicted general palliative care in hospitals as unworthy and highly challenging. This relates to a lack of time and resources, as well as a lack of coordination of palliative treatment, which is often provided late in an illness trajectory. Furthermore, access to palliative care has been limited and offered primarily to patients with cancer, despite international and Danish recommendations that everyone with a life-threatening illness can benefit from this type of care. These challenges seem to be related to organisational and cultural factors, but knowledge on these in a general setting is sparse.

A large Danish regional hospital, with one hospital management and 29 departmental managements, was selected as the case hospital. The study consisted of three sub studies and a mixed-methods design was used.

The first sub study was a quantitative investigation of the organisation and evaluation of general palliative care at the hospital. The study consisted of three independent datasets, all of which evaluated the standard based on the Danish Healthcare Quality Programme on general palliative care (standard 2.19.1.) and therefore could be compared. One of the datasets also shed light on the organisation of the care, by a survey completed by hospital management and all departmental managements.

The comparison of these three datasets showed that there were several discrepancies, which indicated that the current evaluation methods were insufficient. The organisation of care proved to be locally based in the individual departments and did not appear to stem from an overall focus and policy.

More light was shed on this locally based organisation in the second sub study, which was an ethnographic study, investigating the culture of general palliative nursing care in the medical department. The study focused on the context, practice and reflections about this care. Three medical departments at the case hospital were the subject of observational studies and interviews.

The findings of the study showed that the context in which general palliative care was practised was concerned with treatment and efficiency in a time-saving structure; within this context nurses were treatment orientated, which made palliative care a challenge. Furthermore, the practice of palliative care was commenced very late in the course of the illness and could not be provided until *loving care* was ordered. However, there was then only a very small time frame for the provision of this palliative care. The care was based on the individual nurse's personal experience and knowledge which created a fragmented culture in which the care depended on who was on duty.

The third sub study carried out mixed methods merging of the two before mentioned studies, and its purpose was to understand the interactions existing between organisation and culture in order to suggest future interventions. Using a theoretical frame of reference on organisational culture by Joanne Martin, the study found that the different organisational layers (the hospital management, departmental management and the individual nurse) had no common ground for general palliative care, neither with regard to prioritising, policy, nor reference to existing palliative guidelines.

The study finds that future interventions need to address general palliative care as an important and legitimate service provided by the hospital department, and that this needs to be recognised at all organisational levels in order to meet the challenges relating to this type of care being subject exclusively to the personal and professional attitudes of the individual healthcare professional.

The results and findings of the three studies indicate that the hospital's organisational framework, evaluation of the general palliative care and the culture surrounding palliative nursing do not meet the recommendations for this type of care; thus palliative care is not reaching the broad target group which the recommendations prescribe.

Resumé – (Danish Summary)

Det overordnede formål med denne ph.d.- afhandling er at undersøge den basale palliative indsats på sygehuset. Dette ved at beskrive evaluering, organisering, praksis og sygeplejekulturen omkring indsatsen, med henblik på at kunne foreslå brugbare løsninger i det videre arbejde med den palliative indsats.

Både i tidligere forskning og i den offentlige debat er den basale palliative pleje på sygehuset, blevet fremstillet som uværdig og med mange udfordringer. Udfordringerne relaterer sig både til mangel på tid og ressourcer hos de ansatte, men indbefatter også ukoordinerede og sent igangsatte palliative forløb. Herudover er adgangen til den palliative indsats primært begrænset til patienter med en kræftdiagnose til trods for, at både danske og internationale guidelines anbefaler, at alle med en livstruende sygdom kan have gavn af indsatsen. Disse udfordringer ser ud til at være relateret til organisatoriske og kulturelle faktorer, men viden om dette er sparsom.

Afhandlingen tager sit afsæt i et større regionalt dansk case sygehus med én hospitalsledelse og 29 afdelingsledelser. Undersøgelsen har et mixed-method design bestående af tre delstudier.

Første delstudie er en kvantitativ undersøgelse af organisering og evaluering af den basale palliative indsats på sygehuset. Undersøgelsen består af tre uafhængige datasæt, som alle evaluerer standarden fra Den Danske Kvalitetsmodel om den basale palliative indsats (standard 2.19.1.). Det ene datasæt undersøger også organiseringen af indsatsen med et survey udfyldt af sygehusledelse samt alle afdelingsledelser. Sammenligningen af disse tre datasæt viser, at der er adskillige uoverensstemmelser hvilket indikerer, at nuværende evalueringsmetoder ikke er tilstrækkelige. Organiseringen af indsatsen viser sig, at være lokalt forankret i de enkelte afdelinger og ser ikke ud til at fungere ud fra en overordnet tilgang.

Den lokale forankring bliver videre belyst i andet delstudie, som er et etnografisk studie, med formålet at undersøge den basale palliative sygepleje kultur på medicinsk afdeling. Studiet har både fokus på kontekst, praksis og refleksioner omkring indsatsen. I alt tre medicinske afdelinger på case sygehuset er genstand for feltarbejde, som indeholder både observationsstudie samt interviewundersøgelse. Studiet viser, at den kontekst som den basale palliative sygepleje bliver

udøvet i, er præget af behandling og effektivitet i en tidssparende struktur, hvor sygeplejersker er handlingsorienterede. Ydermere ses det i praksis, at palliation bliver igangsat meget sent i sygdomsforløbet og først når der er ordineret *kærlig pleje*. Det er dog et meget lille tidsspektrum denne udfoldelse kan finde sted i. Plejen er baseret på personlige erfaringer og viden hos den enkelte sygeplejerske, hvilket skaber en fragmenteret kultur, hvor plejen afhænger af hvem der er i vagt.

Tredje delstudie er et mixed-method studie bestående af de to ovenstående studier, som har formålet at forstå de interaktioner der eksisterer imellem organisation og kultur. Dette med henblik på at kunne foreslå fremtidige interventioner. Studiet finder, ved hjælp af en teoretisk referenceramme om organisationskultur af Joanne Martin, at de forskellige organisatoriske lag (hospitalsledelse, afdelingsledelse og den enkelte sygeplejerske) ikke har et fælles grundlag i forhold til den basale palliative indsats. Dette både når det handler om prioritering og politik omkring indsatsen, og viden om/brug af eksisterende palliative retningslinjer. Studiet finder, at fremtidige interventioner må adressere den basale palliative indsats som en vigtig og legitim del af de ydelser der ydes på sygehusafdelingen samt, at dette skal anerkendes på alle organisatoriske niveauer.

Resultater og fund i de tre studier indikerer altså, at sygehusets organisatoriske rammer, evaluering af den basale palliative indsats samt kulturen omkring palliative sygepleje ikke er i overensstemmelse med de eksisterende anbefalinger for indsatsen, og ikke når ud til den brede målgruppe, som disse foreskriver.

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Paper 1

Organization and evaluation of generalist palliative care in a Danish hospital.

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Published in BMC Palliative Care May 2015 14, (1) 23

RESEARCH ARTICLE

Open Access

Organization and evaluation of generalist palliative care in a Danish hospital

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Abstract

Background: Hospitals have a responsibility to ensure that palliative care is provided to all patients with life-threatening illnesses. Generalist palliative care should therefore be acknowledged and organized as a part of the clinical tasks. However, little is known about the organization and evaluation of generalist palliative care in hospitals. Therefore the aim of the study was to investigate the organization and evaluation of generalist palliative care in a large regional hospital by comparing results from existing evaluations.

Methods: Results from three different data sets, all aiming to evaluate generalist palliative care, were compared retrospectively. The data-sets derived from; 1. a national accreditation of the hospital, 2. a national survey and 3. an internal self-evaluation performed in the hospital. The data were triangulated to investigate the organization and evaluation of palliative care in order to identify concordances and/or discrepancies.

Results: The triangulation indicated poor validity of the results from existing methods used to evaluate palliative care in hospitals. When the datasets were compared, several discrepancies occurred with regard to the organization and the performance of generalist palliative care. Five types of discrepancies were found in 35 out of 56 sections in the fulfilment of the national accreditation standard for palliative care. Responses from the hospital management and the department managements indicated that generalist palliative care was organized locally – if at all – within the various departments and with no overall structure or policy.

Conclusions: This study demonstrates weaknesses in the existing evaluation methods for generalist palliative care and highlights the lack of an overall policy, organization and goals for the provision of palliative care in the hospital. More research is needed to focus on the organization of palliative care and to establish indicators for high quality palliative care provided by the hospital. The lack of valid indicators, both for the hospital's and the departments' provision of palliative care, calls for more qualitative insight in the clinical staff's daily work including their culture and acceptance of the provision of palliative care.

Keywords: Palliative care, Generalist palliative care, Hospital, Organization, Evaluation, Accreditation

Background

During the last decade it has been emphasized that palliative care is relevant for all life-threatening diseases – not only cancer [1]. According to WHO, palliative care need to be a priority across the healthcare sector and must be established through an overall policy to ensure its structure and financing at all levels [1,2]. At the policy level, this seems to be well accepted [3,4]. In several countries, including Denmark, palliative care is organized at two levels: 1. generalist palliative care and 2. specialist

palliative care [3,5]. Generalist palliative care is defined as care provided to those affected by life-threatening diseases as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team. So, in hospitals, generalist palliative care refers to the care provided by professionals working in non-palliative departments, while specialist palliative care refers to care provided by palliative units [3]. In many countries approximately half of all deaths occur in hospitals [6,7], and in western countries up to 75% of people die from chronic progressive diseases [1]. Hospitals therefore have a significant responsibility to offer and initiate palliative care, and from a quantitative perspective, most

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palliative care is provided at the generalist level. The implementation of palliative care programmes has been shown to affordably improve the quality of care for patients with palliative needs in healthcare organizations [8]. Despite the increasing focus on generalist palliative care, knowledge concerning its organization, evaluation and quality in hospitals is very sparse. Few studies have addressed the implementation of palliative care programmes in hospitals. In California, a recent study showed an increase in the prevalence of palliative care programmes in hospitals from 17% in 2000 to 44% in 2011 [9]. Other studies have shown considerable variations in palliative care practices in hospitals [10,11].

In Denmark, palliative care is approached in the hospitals' national accreditation procedure, the 'Danish Healthcare Quality Programme' - DDKM (a Danish abbreviation for 'Den Danske Kvalitets Model') in the Standard 2.19.1: 'Palliative care of the incurable patient and the patient's relatives'. This standard aims at securing that the institution provides worthy, respectful, evidence-based palliative treatment to the incurable patient, as well as support and care for the patient's relatives.

In June 2011 a large regional hospital went through an accreditation procedure. Later in 2011, a nationwide survey on the Danish hospitals' organization and structure of generalist palliative care was carried out by The Knowledge Centre for Rehabilitation and Palliative Care in Denmark (PAVI-survey), with questionnaires sent to all hospital managements and managers of clinical departments [12]. Two of the questions concerned the departments' fulfilment of the two indicators for Standard 2.19.1. Furthermore, during the 1st quarter of 2012, the hospital carried out a local evaluation of the palliative care standard. In this study, results from these three different approaches studying the generalist palliative care in hospitals were triangulated. The hospital became the subject for testing the hypothesis that the comparison of independently collected data can provide a more precise and detailed picture of the organization and evaluation of generalist palliative care in hospitals.

Aim

The aim of this study was to investigate the organization and evaluation of generalist palliative care in the hospital setting using three existing, independently collected data sources in a Danish hospital.

Methods

This is a retrospective study, where a large regional hospital, which had been the object of three independent evaluations, all describing different aspects of the hospital's delivery of palliative care, was chosen to test the hypothesis of the study. The conditions at this hospital were considered representative of conditions at the large

majority of hospitals in Denmark. Results from the three evaluations were triangulated to describe and identify concordances and/or inconsistencies in the organization, evaluation, prioritization and administration of generalist palliative care.

The hospital was a large, regional teaching hospital with one hospital management and four hospital units (referred to as units 1–4) located in four nearby towns. The hospital covered 30 clinical specialties, had 1,060 beds and 4500 employees. Some of the departments had sections located in more than one unit, though they were led by one departmental management.

Palliative guidelines were developed in April 2011 for common use in all hospitals located in the same region as the hospital in question. The guidelines were based on the requirements described in DDKM's Standard 2.19.1 and approved by the Head of the Palliative Care Unit in the case hospital. The guidelines were accessible to all staff using the region's internal document management system.

In the period from summer 2011 to spring 2012, the hospital was the object of three different studies/evaluations, where data on the hospital's approach to the delivery of generalist palliative care could be acquired (Figure 1). All three studies had evaluated Standard 2.19.1 for palliative care in different ways, and the organization and administration of generalist palliative care was approached more thoroughly in the PAVI survey. Results from the three individual studies will be presented in the methods section, because they comprise the data on which the triangulation is based. The presentation of these results in the methods section will provide the basis for interpreting the results of the triangulation and the subsequent discussion.

The external accreditation procedure by IKAS

The hospital initially went through the national accreditation procedure performed by The Danish Institute for Quality and Accreditation in Healthcare, known as IKAS, which manages, develops and plans the DDKM programme [13]. IKAS uses accreditation standards to ensure an impartial assessment of the hospitals' conditions for providing services of high quality. As mentioned earlier palliative care is approached in DDKM as Standard 2.19.1: 'Palliative care of the incurable patient and the patient's relatives'. The aim of this standard is to ensure that the patient experiences worthy, respectful, empathic palliative treatment when active treatment is pointless and that the patient's relatives are involved in the palliative course in a worthy and respectful way, when desired by the patient. The target group for this standard is managers and staff in sections providing palliative treatment. Two indicators have to be fulfilled to comply with the standard – Indicator 1: presence of guidelines

1. IKAS national accreditation procedure – data from the hospital**

Period: 16-20 June 2011
Participants: Entire hospital
Methods: Interviews, observation, and checking of patient records performed by 7 external surveyors from IKAS (doctors and nurses), according to IKAS' evaluation principles
Results: Standard 2.19.1. for palliative care was 'met in full' at the level of Indicator 2**
Comments: No information could be provided regarding the basis for the IKAS surveyors' conclusion for the hospital in the accreditation procedure

2. National Survey by PAVI[□] – data from the hospital

Period: December 2011 - March 2012
Participants: The hospital's management (N=1) and the departments' managers (N=29)
Methods: Questionnaire. 4 themes concerning the structure and organisation of general palliative care (PC): 1. Policy for and focus on PC. 2. Allocation of resources to PC. 3. Instructions/guidelines for PC. 4. Registration of PC.
Results: The response rate was 100%. The answers are shown in Table 1

3. Hospital's internal evaluation

- 3.1. Departments' self-evaluation of Standard 2.19.1
- 3.2. Internal audit of the Standard's implementation

Period: 1st quarter 2012

**3.1. Self-evaluation performed by the departments' own 'key quality staff'**

Participants: 56 sections from 23 departments
Methods: Each department had key quality staff to register in a database (called TAK and provided to the hospital by IKAS) whether Standard 2.19.1 was 'met in full' or 'partially met' at the level of Indicator 2 by each section
Results: 41 sections (18 departments) met the guideline 'in full'; 11 sections (7 departments) met it 'partially'. In 1 section it was 'not met', and in 3 sections, the Standard was found 'not relevant' (The results are shown in Table 2)

**3.2. Internal audit by the region's survey corps, performed independently from Part 3.1**

Participants: 17 sections from 13 departments
Methods: A survey corps interviewed the staff and checked patient records to see if Standard 2.19.1 was implemented according to the requirements described in DDKM*
Results: 10 sections (9 departments) received comments: 6 had 'positive' comments, and 7 had comments that 'attention was required'. Both types of comments could be used in the same section
Comments: It was not possible to obtain information on the number of interviews, or how many patient records the survey corps had checked

*IKAS: The Danish Institute for Quality and Accreditation in Healthcare is responsible for the accreditation of Danish hospitals according to DDKM (The Danish Quality Model)

** Indicator 1: The institution has guidelines for palliative care, and Indicator 2: Leaders and members of staff are familiar with the guidelines and use them

[□]PAVI: The Knowledge Centre for Rehabilitation and Palliative Care (in Denmark)

Figure 1 The three datasets used for triangulation.

for the institution's provision of palliative care and Indicator 2: managers and staff are familiar with and use the guidelines.

Results from IKAS' data

IKAS evaluated Standard 2.19.1 as having been 'met in full' by the hospital at the level of Indicator 2. Because of the existence of common palliative guidelines for all hospitals in the region, it is evident that the standard could be evaluated as fulfilled at the level of Indicator 1: the presence of guidelines. However, on the level of Indicator 2 it was not possible to obtain a specification from IKAS regarding the basis for the surveyors' conclusion. IKAS' general evaluation principles can be found on the internet [13], but these principles do not offer any further clarification on the subject.

The PAVI-survey

The hospital participated in the nationwide PAVI-survey, designed to map the organization and structure of Danish hospitals' provision of generalist palliative care. All clinical departments with patient contact received a questionnaire concerning the organization and structure of palliative care in the department, categorized into different themes. The national overall response rate among 410 departments was 78%, and data from the case hospital were extracted for this study. A report of the full survey can be found elsewhere [12].

Results from PAVI-survey

Both the management of the hospital ($n = 1$), and all of the hospital's clinical department managers ($n = 29$) responded to the survey. One manager from a surgical department declined to have palliative patients among the department's clientele and commented that the department 'did not treat cancer patients'. Six departments answered 'no' to provide palliative care – one paediatric, one surgical, and four miscellaneous. The remaining 22 departments' managers confirmed that they sometimes did provide palliative care, and they were further questioned with regard to their departments' organization and provision of palliative care. The responses relevant for this study are shown in Table 1, and compared with answers from the hospital's management.

The hospital's internal evaluation

The hospital went through a self-evaluation as part of the accreditation process. IKAS recommends that self-evaluations be carried out between the external accreditation procedures, which take place every three years. The aim of self-evaluations is to ensure and encourage development and fulfilment of the standards. The self-evaluation consists of two parts – 3.1: a self-evaluation performed by key quality personnel in the

clinical departments, and 3.2: an audit conducted by a survey corps in selected departments (Figure 1). Key quality personnel are persons, usually nurses, employed in the departments with a view to implementing the accreditation-standards. Survey corps are trained in the regions where the hospitals are located. The internal survey aims to evaluate to what extent the palliative guideline has been implemented and to identify needs for improvement in order to fulfil the indicators [13].

Results from the hospital's internal evaluation

Part 1) The departments' self-evaluation Among 23 departments, 56 evaluations were retrieved from the different wards and outpatient clinics (Table 2). Six of the hospital's 29 clinical departments did not participate in the self-evaluation – two medical departments and four miscellaneous. The results were registered by the key quality staff in a documentation system called TAK, provided to the hospital by IKAS. Of the 56 evaluations, 41 (representing 18 departments) were evaluated as having met the indicator targets in full (Table 2).

An overview of the departments that participated in the hospital's self-evaluation and in the PAVI-survey is shown in Table 2.

Part 2) Audit of selected departments The survey corps, trained by the region, had planned to visit all the somatic departments, but only 13 departments were audited (the reasons for this could not be revealed). The departments' managers were contacted prior to the visit and they agreed with the surveyors on which sections should be audited. The audit was carried out in 17 sections from the 13 departments. Ten departments received comments on the palliative standard 2.19.1 (Table 2). The findings could be categorized as a "positive grade" (fulfilling the indicator targets) or findings that "required attention" (deviation from fulfilling the indicator targets), and it was possible to get both types of comments within the same section. Six sections did not receive any comments, six sections were graded 'positive' and seven sections had findings that 'required attention'. The comment 'require attention' could, for instance, refer to a lack of knowledge on the palliative standard, a lack of private rooms for conversations, a lack of documentation about information given to relatives, or non-adherence to the Edmonton Symptom Assessment System (ESAS) as requested in the hospital's common palliative guideline.

Statistics

Descriptive statistics are used to present the results of the triangulation.

Table 1 The hospital's and departments' managers' responses to the PAVI-survey concerning organization and prioritisation of palliative care (PC)

Hospital's management (N = 1)		Departments' managers (N = 22)	Disagreements
Question answer		Question answer	Between hospital's and departments' managers
Theme 1. Policy for and focus on palliative care			
Does the hospital have a general policy for PC*?	Does the hospital have a general policy for PC?		
	Yes:	6 (27%)	Disagreement
	No:	11 (50%)	
	Don't know	5 (23%)	
	Does the department have a policy for PC?		
	Yes:	9 (41%)	Incomparable
	No:	12 (55%)	
	Don't know:	1 (4%)	
	Does the department focus on PC?		
	Yes:	22 (100%)	Incomparable
	Who creates focus on PC in the department?		
	Department's managers:	18 (82%)	
	Hospital's management:	6 (27%)	Incomparable
	Doctors:	15 (64%)	
	Caregivers:	17 (77%)	
Dedicated staff:	2 (9%)		
Specialised PC:	9 (41%)		
Other:	1 (4%)		
Are there an ongoing dialogue between the hospital's and departments' managers	Does the department management have an ongoing dialogue with the hospital's management concerning PC?		
	Yes, satisfactory:	6 (27%)	Disagreement
	Yes, but insufficient:	1 (4%)	
	No, dialogue is missing:	5 (23%)	
	No, not applicable:	3 (14%)	
	No, not necessary:	7 (32%)	
	Theme 2: Allocation of resources to palliative care		
The hospital's framework for PC involves?	Has the hospital's management provided a framework for the department's PC?		
Time provided to increase staff's qualifications	Yes:	6 (27%)	Disagreement
	No:	13 (59%)	
	No answer:	3 (14%)	
	Has the department allocated resources specifically for PC?		
	Yes:	7 (32%)	Incomparable
	No:	15 (68%)	
Theme 3. Instructions/guidelines for palliative care			
Has the hospital established general instructions/guidelines for PC?	Does the department have instructions/ quidelines for PC?		

Table 1 The hospital's and departments' managers' responses to the PAVI-survey concerning organization and prioritisation of palliative care (PC) (Continued)

			Disagreement
Don't know	Yes:	12 (55%)	
	No:	10 (45%)	
Has the hospital a procedure for implementation of general instructions and guidelines?			
Yes			Incomparable
Theme 4: Registration of palliative care			
Is PC registered in the department?			
	Yes:	7 (32%)	Incomparable
	No:	9 (41%)	
	Don't know:	3 (14%)	
	N/A:	3 (14%)	
Does the hospital have administrative tools for the registration of general PC?		Does the department have administrative procedures for the registration of PC?	
	Yes:	4 (18%)	Disagreement
	No:	13 (59%)	
Don't know:	Don't know:	4 (18%)	
	N/A:	4 (4%)	
Does the hospital lack administrative tools for general PC?		Is there a need for administrative procedures for the registration of PC?	
	Yes:	1 (4%)	Disagreement
	No:	6 (27%)	
Don't know:	Don't know:	6 (27%)	
	Did not answer:	9 (41%)	
		Are there DRG-codes for the registration of the department's PC?	
	Yes:	5 (23%)	Incomparable
	No:	7 (32%)	
	Don't know:	10 (45%)	

Ethical considerations

The study was performed in accordance with the Declaration of Helsinki. The Danish Data Protection Agency registered the study. According to the Regional Committee for Medical research, ethical approval was not required. Consent to use the data was obtained from the hospital's management and the departments' managers.

Results

The results from the triangulation of the three studies will be presented in this section.

The departments that participated in the PAVI-survey and the internal evaluation of Standard 2.19.1 are shown in Table 2.

The hospital's fulfilment of Standard 2.19.1

Five types of discrepancies could be identified when the results from the three studies of the hospital's and

its departments' fulfilment of Standard 2.19.1 were triangulated. The discrepancies could be identified among 35 sections, representing 19 departments, and the distribution of these discrepancies is shown in Table 3:

Discrepancy 1: In the PAVI-survey 15 departments stated that they did not have a palliative guideline/instruction, while in the self-evaluation they claimed to have fulfilled Standard 2.19.1 fully or partially.

Discrepancy 2: Two departments assessed the use of the standard in the self-evaluation as "not relevant" despite having responded in the PAVI-survey that their department provided palliative care.

Discrepancy 3: Eight departments did not provide palliative care according to the PAVI-survey, however in the self-evaluation the departments' internal surveyors all stated that the standard was met in full.

Table 2 Departments participating in the PAVI-survey and in the hospital's internal evaluation of Standard 2.19.1

PAVI-survey*			Hospital's self evaluation**							
Type of department	Responders	Providers of palliative care	Departments' self-evaluation				Audit			
			Sections involved	[Departments involved]	Standard 2.19.1 was:				Sections involved	Comments
					Fully met	Partially met	Not met	Not relevant		
N	29	22	56	[23]	41 [18]	11 [7]	1 [1]	3 [3]	17 [13]	10 [9]
Medical	8	8	16	[6]	9 [3]	6 [4]	1	0	6 [4]	3 [2]
Surgical	7	5	19	[7]	15 [6]	4 [2]	0	0	5 [3]	3 [3]
Paediatric	2	1	6	[2]	5 [2]	0	0	1	0	0
Oncology/haematology	2	2	2	[2]	2 [2]	0	0	0	2 [2]	2 [2]
Anaesthesiology	3	3	8	[3]	7 [3]	1	0	0	1	1
Gynecology/obstetrics	2	2	4	[2]	3 [2]	0	0	1	2	1
Miscellaneous	5	1	1	[1]	0	0	0	1	1	0

*A national survey concerning the organisation and structure of palliative care in Danish clinical hospital departments (N = 410). Here, the responses from the case hospital's 29 participating departments are shown.** The self evaluation concerned 56 sections' fulfilment of Standard 2.19.1: 'Treatment of the incurably ill patient and care for the patient's relatives', Version 1, at the level of Indicator 1: The institution has guidelines for palliative care, and Indicator 2: Leaders and members of the staff are familiar with the guidelines and use them.# Of the 29 PAVI-survey responders, 6 departments did not join the selfevaluation: 2 medical departments, 1 audiology, 1 eye, 2 emergency room.

‡Miscellaneous consists of departments: Eye department, dermatology, audiology and 2 ER's (emergency room).

\$All numbers written in parenthesis refers to the number of departments (in all 23 departments encompassing the 56 sections involved in the self-evaluation).

Discrepancy 4: In the internal audit, four of the sections had comments that 'required attention', despite having responded in the self-evaluation that they met the standard in full.

Discrepancy 5: In the self-evaluation, 12 departments assessed Standard 2.19.1 as having been "partially" met or "not met", despite the fact that Standard 2.19.1 was assessed by IKAS as having been "met in full" at the level of Indicator 2.

For six departments, more than one discrepancy could be identified.

Organization of generalist palliative care (PAVI-survey)

The responses from the hospital's management and the departments' managers in the PAVI-survey were compared. Several disagreements were identified concerning the four themes shown in Table 1: 1. Policy for and focus on palliative care, 2. Allocation of resources to palliative care, 3. Instructions/guidelines for palliative care, and 4. Registration of palliative care. The hospital's management answered 'no' to the survey's first question, "Does the hospital have a general policy for palliative care?", while 27% of the departments' managers answered 'yes' to the same question. From the responses by the departments' managers, 41% responded that their own department had a policy for palliative care. The hospital's management did not find itself engaged in a dialogue with the departments concerning palliative care; however, 27% of the departments' managers found the

dialogue satisfactory, 23% missed a dialogue, and 32% found it 'unnecessary'. The hospital's management was unaware of the guideline for palliative care common to all hospitals in the region. Despite the existence of this common guideline, almost half of the departments' managers (45%) responded that their department had no guidelines for the provision of palliative care (as requested to fulfil Indicator 2 of the Standard 2.19.1). The focus on palliative care was primarily created by the department managers, doctors and caregivers.

The hospital's management responded to provide resources for generalist palliative care, by allowing the staff time to improve their qualifications. However, only seven out of the 22 departments (32%) responded that resources had been allocated specifically for the departments' provision of generalist palliative care. Neither the hospital's management nor the departments' managers were concerned that the departments had no registration procedures for their provision of palliative care. The hospital's management was unaware whether it was at all possible to register generalist palliative care, and only one department expressed a need for this type of registration.

Discussion

This study has shown that generalist palliative care was organized and prioritized differently within the various departments, and that there was no overall policy or goal for the hospital's provision of palliative care. The Danish National Board of Health's recommendations for palliative care include having a common policy for palliative

Table 3 Discrepancies in the departments/sections evaluations of Standard 2.19.1 were identified in 35 cases

Sections N = 35	Hospital's self-evaluation Departments' self evaluationStandard met?	Internal audit*	PAVI -survey Providing palliative care	Instructions/ guidelines for palliative care**	IKAS-data Accreditation of standard 2.19.1	Discrepancies 1-5
Unit 1 Medical	Fully	NC	Yes	No		1
Unit 1 Medical	Fully	NA	Yes	No		1
Unit 1 Medical	Fully	NA	Yes	No		1
Unit 1 Medical	Fully	NA	Yes	No		1
Unit 1 Medical	Fully	NA	Yes	No		1
Unit 1 Medical	Fully	NA	Yes	No		1
Unit 1 Medical	Partially	RA	Yes	No		1 + 5
Unit 1 Medical	Partially	NA	Yes	Yes		5
Unit 2 Medical	Partially	NA	Yes	Yes		5
Unit 2 Medical	Not met	NC	Yes	Yes		5
Unit 2 Medical	Partially		Yes	Yes		5
Unit 2 Medical	Partially		Yes	Yes		5
Unit 3 Medical	Partially	RA + P	Yes	Yes		5
Unit 1 Oncology	Fully	RA	Yes	Yes	Indicator 1 and Indicator 2 were both met in full by all the departments	4
Unit 1 Haematol	Fully	RA	Yes	No		1 + 4
Unit 2 Surgical	Fully	NA	No	NQ		3
Unit 2 Surgical	Fully	NA	No	NQ		3
Unit 2 Surgical	Fully	NA	No	NQ		3
Unit 2 Surgical	Fully	NA	No	NQ		3
Unit 2 Surgical	Partially	P	Yes	Yes		5
Unit 2 Surgical	Partially	NA	Yes	Yes		5
Unit 1 Surgical	Fully	NA	Yes	No		1
Unit 3 Surgical	Partially	RA	Yes	No		1 + 5
Unit 3 Surgical	Partially	P	Yes	No		1 + 5
Unit 3 Surgical#	Fully	NA	No pall pttts #	NQ		3
Unit 3 Gyn/obs	Fully	RA + P	Yes	Yes		4
Unit 1 Gyn/obs	Not Relevant	NA	Yes	Yes		2
Unit 2 Anesth	Partially	NA	Yes	No		1 + 5
Unit 2 Anesth	Fully	RA	Yes	No		1 + 4
Unit 1 Miscellaneous	Not relevant	NC	Yes	No		2
Unit 1 Paediatric	Fully	NA	No	NQ		3
Unit 1 Paediatric	Fully	NA	No	NQ		3
Unit 1 Paediatric	Fully	NA	No	NQ		3
Unit 3 Paediatric	Fully	NA	Yes	No		1
Unit 3 Paediatric	Fully	NA	Yes	No		1

*Audit's comments: P - positive - confirm indicator targets were met. RA - requires attention - discrepancy in fulfilling the indicators. NC - no comments. NA - no audit. ** NQ - not questioned survey# according to the PAVI-survey, this department did not treat palliative patients.

#Types of discrepancies identified in the triangulation of the 3 dataset: Discrepancy 1: Departments stating in the PAVI-survey 'not to have a palliative guideline/instruction', while Standard 2.19.1 was fully or partially fulfilled according to the self evaluation. Discrepancy 2: Departments stating in the self-evaluation that use of the standard was "not relevant", while responding in the PAVI-survey that their department 'did provide palliative care'. Discrepancy 3: Departments stating in the PAVI-survey 'not to provide palliative care', while they fulfilled the standard according to the selfevaluation. Discrepancy 4: Departments that stated to 'meet the standard in full' in the self-evaluation, but received a comment in the audit that they 'required attention' Discrepancy 5: Departments that stated to fulfil Standard 2.19.1 only "partially" or "not met" in the self-evaluation, but were assessed by IKAS to "meet the Standard in full", at the level of Indicator 2.

care in place, as well as joint efforts from the hospitals to identify patients in need of palliative care [3], although appropriate methods for early identification of these patients remains to be documented [14]. Evidence exists that early, targeted and systematic palliative care for patients with life-threatening diseases allows for better symptom management and fewer hospitalisations [15–17]. To support this, integrated trajectory palliative care models [18] have been recommended and developed in order to ensure that such services are well coordinated. However, knowledge regarding integration of these models in generalist palliative care is yet to be explored. In general, systematically implemented clinical pathways have indicated a beneficial effect, with fewer hospital complications and improved documentation [19]. However, these effects have not yet been shown specifically with regard to end-of-life care pathways [20].

The hospital's fulfilment of the accreditation standard for palliative care

The triangulation of the three datasets identified various discrepancies when the responses to similar questions concerning the fulfilment of the standard for palliative care were compared. The national accreditation procedure concluded that the hospital completely fulfilled the quality standard for palliative care. This conclusion must be designated as invalid, considering the discrepancies that were identified when the results from the two other datasets were evaluated. To fulfil the quality standard it was mandatory to have guidelines in place for the departments' provision of palliative care, and to know about and use the guidelines. However, in the PAVI survey 15 out of 22 department managers declined to have instructions for palliative care, and in the self-evaluation the standard was not met or only partially met by several departments. This raises the question on 'how to evaluate the quality of palliative care' – which indicators and which methods are useful and valid? Based on this study, it seems apparent that the quality of palliative care provided by the hospitals cannot be described or certified only by performing the national accreditation procedure. Even if the results of the DDKM accreditation had seemed valid, there is still a lack of proof between the existence and awareness of guidelines for palliative care and the provision of high quality palliative care.

There is an ongoing discussion regarding to what extent the use of 'health sector accreditation' improves the quality of care provided to patients and their relatives [21]. In a Cochrane Review from 2011 [22], the external inspection of compliance with other kinds of standards could not be demonstrated to improve quality; however, only a small number of studies have focused on this issue. In the US, the Joint Commission on Accreditation of Healthcare Organizations, certification of palliative care

programs, has been included in the accreditation procedures for several years [23]. Hospitals accredited by The Joint Commission have shown a higher performance with regard to adherence to quality measures compared with non-accredited hospitals [24]. Whether this adherence results in better quality, or whether the results were due to biases caused by differences in the hospitals' characteristics, remains unclear. So, internationally the discussion of accreditation procedures as usable markers for good quality continues [25]. Detailed quality indicators for palliative care have been lacking [26], and efforts are being made to develop quality indicators applicable to all palliative care settings [27]. Recently, palliative care experts were asked to score the relevance and usability of different quality indicators for national healthcare systems' organization of palliative care for patients with cancer and dementia [28]. They seemed to have reached consensus on 23 indicators covering both the access to a specialist palliative care team, infrastructure, continuity, documentation and education of all professionals providing palliative care. However, the difficulties in measuring the quality of palliative care can advocate for more qualitative studies [29]. The patients' and the relatives' viewpoints must be considered [30], as well as the challenges the professionals are facing in caring for patients in common clinical departments [31–34].

Organization of generalist palliative care (disagreements between hospital and departmental managements)

In our study, the delivery of high quality palliative care did not seem to be regarded as a shared task for the hospital's departments, judged by the disagreements identified in the answers from the hospital's management and the departments' managers. Even within single departments, the triangulation of the data revealed discrepancies between the responses from the departments' managers and their key quality staff, and between the key quality staff and the region's audit corps. So, both on the level of the hospital and among several of the departments, there was no common approach to ensure a high quality palliative care at the generalist level for patients and their relatives.

The PAVI-survey revealed a general lack of resources specifically allocated to the provision of generalist palliative care. It remains speculative whether this means that this type of care is not regarded as a part of the department's productivity and 'just' has to be delivered within the 'existing frames' of the department's activities and budget. The managers did not seem specifically interested in registering the departments' provision of palliative care. In fact, within the hospitals' reimbursement system no DRG-codes exist for generalist palliative care; only on the level of specialized palliative care is there a DRG-code available for palliative treatment. It remains unknown whether the lack of productivity registration influences the

quality of the care delivered. Research has shown that financial support in health care may have an effect in changing the practice of healthcare professionals when a payment is given for each service, but without evidence in patient outcome [35]. Factors such as lack of resources and lack of time have been shown to be barriers to providing palliative care in the hospital setting [36]. Time is necessary to get to “know” the patient to be able to offer individualized care and relief [37]. If no extra resources are allocated to this aspect of caring for patients with life-threatening diseases, then it is likely that the time-consuming tasks will be given lower priority when the productivity of the departments is in focus.

In very many ways the organization and accreditation of the Danish hospital system resembles the hospital and accreditation systems in other western countries [38]. Therefore, the implications and relevance of the results presented here are likely to be of importance both to healthcare professionals and continuous research in the provision of generalist palliative care, and the search for valid quality indicators. Hospital systems must relate to their reputation of being ‘the most undesirable setting for place of death’ [39] and to the fact that the quality of end-of-life care for their dying patients is described worldwide as poor [40]. The challenges of organizing and evaluating generalist palliative care are issues for the Danish healthcare system as well as for European systems and globally.

Strengths and limitations

The use of existing data sources in data triangulation is both a weakness and a strength. It is a weakness because we did not know the considerations that lay behind the responses, and owing to the retrospective design we were unable to influence the content of the questions for our purpose and the persons questioned. Two of the three evaluations of the ‘palliative care performance’ were based on self-reporting. A tendency for over-estimation of adherence to guidelines in self-reported situations has been demonstrated [41]. This advocates that self-reporting should not be the only method used to evaluate clinical practice. The strength of the data triangulation lies in the independence between the three data sets, which allowed us to approach biases caused by self-reported over-estimation, and to question the validity of the external accreditation procedure. Furthermore, the variation of data can describe the field with more breadth.

This study only encompasses results from a single hospital, which is a limitation. However, the hospital was a large regional hospital, with an organization and administration similar to other hospitals of this size in Denmark. When the responses from the hospital were compared with the responses reported in the national PAVI-study [12], the hospital also appeared to be representative of hospitals in Denmark in general.

Conclusion

This study demonstrates a lack of an overall policy, organization and goals for the provision of palliative care, as recommended by the national recommendations for palliative care. Invalid results and weaknesses in the existing evaluation methods for the quality of generalist palliative care have been demonstrated. There is a need for more research focusing both on optimization of the hospitals’ and their clinical departments’ organization of generalist palliative care, and for indicators that can ensure that patients and relatives receive high quality palliative care when they need it. The lack of valid indicators both for the hospitals’ and the departments’ organization and provision of palliative care, and the quality of the care, calls for more qualitative insight into the clinical staff’s daily work, their culture and acceptance of the provision of palliative care to those in need. So far, no gold standard for high quality generalist palliative care seems to exist.

Abbreviations

DDKM: The Danish Healthcare Quality Programme; IKAS: Institute for Quality and Accreditation in the Danish National Health Service; PAVI: Knowledge Centre for Rehabilitation and Palliative Care (in Denmark); DRG: Diagnosis-related group.

Competing interests

The authors declare that they have no competing interests.

Authors’ contributions

HB carried out the study design, data analysis and drafted the manuscript. BBH participated in the study design and coordination and helped to draft the manuscript. LJ conceived the design of the study, commented on the data analysis and contributed to the manuscript in collaboration with the first and second authors. All authors read and approved the final manuscript.

Acknowledgements

We are grateful to the following foundations, which provided financial support to the project: the Novo Nordisk Foundation; Hospital North, Region Zealand, Denmark and the Health Research Foundation in Region Zealand. We wish to thank the hospital management and all department managements at the case hospital for permission to use their responses. Our thanks are extended to PAVI for allowing us to use data from the national investigation, and to consultant Nete Munk Villebroe for providing us with information about DDKM.

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Received: 16 January 2015 Accepted: 23 April 2015

Published online: 06 May 2015

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Paper 2

The Culture of General Palliative Nursing Care in Medical Departments - An Ethnographic Study.

Bergenholtz H, Jarlbæk L, Hølge-Hazelton B

Published in the International Journal of Palliative Nursing April 2015. 2;21(4):193-201

OBS: Denne artikel er ikke tilgængelig i open access, og er derfor ikke med i denne pdf-udgave.

Paper 3

Generalist palliative care in hospital – cultural and organisational interactions. Results of a mixed-methods study.

Bergenholtz H, Jarlbæk L, Hølge-Hazelton B

E-published ahead of print in Palliative Medicine December 2015

OBS: Denne artikel er ikke tilgængelig i open access, og er derfor ikke med i denne pdf-udgave.

Appendix 1: Survey from PAVI to hospital managements and departmental managements

Kortlægning III: spørgeskema til sygehusledelser

YLUA-RXME-8GL2

Distributionsform

☒ E-mail ☐ Papir ☐ Brevfletning

E-mail

Region

Sygehusnummer

Sygehus

YLUA-RXME-8GL2

National kortlægning af hospitalernes palliative indsats på basisniveau

Kære Sygehusledelse

Dette spørgeskema henvender sig til sygehusledelser på alle danske hospitaler. Det er udsprunget af den seneste tids forventninger/krav fra regionerne til sygehusledelserne om, at der fokuseres på den palliative indsats, for alle patienter, som har livstruende sygdom, der ikke er forbigående (her kaldt palliative patienter). Det omfatter både patienter med og uden kræft.

Spørgeskemaet omhandler hospitalets målsætninger og organisering vedrørende den palliative indsats. Respondenterne til de enkelte skemaer vil kun være kendt af Palliativt Videncenter (PAVI). Svarene vil blive håndteret fortroligt og præsenteret i anonymiseret form.

Det tager ca. 15-20 minutter at besvare spørgeskemaet. Din besvarelse bliver først sendt til os, når du på sidste side trykker på krydset i nederste højre hjørne.

Skemaet indeholder 5 forskellige temaer udover de indledende spørgsmål. Efterhånden som du udfylder spørgeskemaet, viser en bjælke nederst i billedet, hvor langt du er nået.

Hvis du har spørgsmål, er du velkommen til at kontakte projektleder Lene Jarlbæk på lj@pavi.dk eller tlf. 3038 2349.

Mange tak for din hjælp!

YLUA-RXME-8GL2

INDLEDENDE SPØRGSMÅL

Sygehus

Respondentens stilling

Respondentens kontaktdata (opbevares fortroligt, kun tilgængeligt for PAVI)

Email

Telefonnummer

Navn

YLUA-RXME-8GL2

Den indsats, vi vil spørge til i det følgende, er WHO's definition af palliativ indsats:

Definition af palliativ indsats (WHO 2002)

Palliativ indsats er "at fremme livskvaliteten hos patienter og familier, som står over for de problemer, der er forbundet med livstruende sygdom, ved at forebygge og lindre lidelse gennem tidlig diagnosticering og umiddelbar vurdering og behandling af smerter og andre problemer af både fysisk, psykisk, psykosocial og åndelig art".

Vurderet ud fra ovenstående definition kan nogle af hospitalets ydelser så betegnes som "palliativ indsats"?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

Har hospitalet en overordnet politik for den palliative indsats?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

YLUA-RXME-8GL2

HOSPITALET'S POLITIK FOR DEN PALLIATIVE INDSATS

Hvornår er den overordnede politik for den palliative indsats blevet udstukket?

☐ Inden for det seneste år ☐ Inden for de seneste 2-3 år ☐ Mellem 3 og 5 år siden ☐ Mere end 5 år siden ☐ Ved ikke

Kommentarer

Hvem har taget initiativ til at etablere en overordnet politik for den palliative indsats? (sæt gerne flere x)

☐ Regionen ☐ Hospitalets ledelse ☐ Afdelingsledelserne ☐ Personalet på afdelingerne ☐ En eller nogle få indsjæle ☐ Andet (uddyb i kommentarer) ☐ Ved ikke

Kommentarer

YLUA-RXME-8GL2

Hvor kan patienter og/eller pårørende få information om hospitalets politik for den palliative indsats? (sæt gerne flere x)

☐ I skriftligt materiale, der udleveres til alle patienter ☐ I skriftligt materiale, der udleveres til de patienter, for hvem personalet finder oplysningerne relevante ☐ I skriftligt materiale, som står fremme på afdelingerne ☐ I skriftligt materiale, der udleveres på forespørgsel ☐ På hospitalets hjemmeside (anfør gerne link i kommentarer) ☐ Informationen er ikke offentligt tilgængelig ☐ Der findes ingen information ☐ Andet (uddyb i kommentarer) ☐ Ved ikke

Kommentarer

Hvordan får afdelingerne kendskab til hospitalets overordnede politik for den palliative indsats? (sæt gerne flere x)

☐ I skriftligt materiale, der udleveres til afdelingsledelsen med jævne mellemrum ☐ I skriftligt materiale, der engang er blevet udleveret til afdelingsledelserne ☐ I skriftligt materiale, der løbende

udleveres til nyansatte læger og plejepersonale ☐ I skriftligt materiale, der engang er blevet udleveret til alle læger og plejepersonale ☐ Via hospitalets hjemmeside (anfør gerne link i kommentarer) ☐ Via fællesmøder på hospitalet ☐ Sådanne initiativer er endnu ikke iværksat ☐ Andet (uddyb gerne i kommentarer) ☐ Ved ikke ☐

Kommentarer

YLUA-RXME-8GL2

Har hospitalet en overordnet politik for, at afdelingerne kan tilbyde åbne indlæggelser til de palliative patienter?

☐ Ja ☐ Nej ☐ Ved ikke ☐

Kommentarer

Hvem fastlægger antallet af åbne indlæggelser for en afdeling?

☐ Antallet af åbne indlæggelser er ikke fastlagt ☐ Antallet af åbne indlæggelser besluttet af afdelingsledelsen ☐ Antallet af åbne indlæggelser besluttet af sygehusledelsen ☐ Andet ☐ Ved ikke ☐

Kommentarer

Hvordan fastlægger sygehusledelsen antallet af åbne indlæggelser for en afdeling?

☐ Et max antal pr. givent tidspunkt ☐ Et max antal hen over 1 måned ☐ Et max antal hen over 1 år ☐ Andet (uddyb i kommentarer) ☐ Ved ikke ☐

Kommentarer

YLUA-RXME-8GL2

Har hospitalet en overordnet politik for samarbejde med primærsektoren omkring palliative patienter?

☐ Ja ☐ Ja, men politikken er endnu ikke implementeret ☐ Nej ☐ Ved ikke ☐

Kommentarer

Evalueres implementeringen af hospitalets politik for den palliative indsats løbende?

☐ Ja ☐ Nej ☐ Ved ikke ☐

Kommentarer

Hvor ofte evalueres implementeringen af hospitalets politik for den palliative indsats?

☐ Hvert år ☐ Hvert andet år ☐ Hvert femte år ☐ Endnu ikke relevant ☐ Andet (uddyb i kommentarer) ☐ Ved ikke
Kommentarer

YLUA-RXME-8GL2

I Danmark er den palliative indsats organiseret i:

en specialiseret indsats, som omfatter palliative teams, enheder, afdelinger og hospices, hvor personalet er specialuddannet i palliation og kun beskæftiger sig med palliation

og

en basal indsats, som foregår på sygehusafdelinger, blandt praktiserende læger og på kommunalt niveau, hvor personalet ikke er specialuddannet, og hvor palliation kun er en delmængde af de opgaver, stedet skal løse.

Hvilken del af den palliative indsats omfattes af hospitalets politik?

☐ Kun den specialiserede indsats ☐ Kun den basale indsats ☐ Palliation generelt (omfatter både den specialiserede og den basale indsats) ☐ Ved ikke
Kommentarer

YLUA-RXME-8GL2

ORGANISERINGEN AF DEN PALLIATIVE INDSATS

ORGANISERINGEN AF DEN PALLIATIVE INDSATS

De følgende spørgsmål vedrører hospitaler, hvor en palliativ indsats ydes, uanset om indsatsen er basal og/eller specialiseret.

I Danmark er den palliative indsats organiseret i:

en specialiseret indsats, som omfatter palliative teams, enheder, afdelinger og hospices, hvor personalet er specialuddannet i palliation og kun beskæftiger sig med palliation

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På hvilket niveau foregår hospitalets palliative indsats?

☐ Kun på basalt niveau ☐ Kun på specialiseret niveau ☐ Både på basalt og specialiseret niveau ☐

Andet (uddyb i kommentarer) ☐ Ved ikke

Kommentarer

YLUA-RXME-8GL2

Kan hospitalet tilbyde en specialiseret palliativ indsats inden for sin egen organisation?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

Hvilken specialiseret indsats kan hospitalet tilbyde? (sæt gerne flere x)

☐ Palliativ Team ☐ Palliativ Enhed ☐ Andet (uddyb i kommentarer) ☐ Ved ikke

Kommentarer

Har hospitalet en aftale om adgang til en specialiseret palliativ indsats, der organisatorisk ikke hører til hospitalet?

☐ Ja ☐ Nej ☐ Andet (uddyb i kommentarer) ☐ Ved ikke

Kommentarer

YLUA-RXME-8GL2

Er sygehusledelsen i dialog med afdelingsledelserne om den palliative indsats på basisniveau?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

HOSPITALET'S RAMMER FOR DEN BASALE PALLIATIVE INDSATS

De følgende spørgsmål vedrører hospitalets indsats på basisniveau (IKKE på specialiseret niveau).

Hospitalets rammer for den basale palliative indsats involverer (sæt gerne flere x)

☐ Personale, specielt ansat mhp. den basale palliative indsats ☐ Fysiske rammer til den basale palliative indsats ☐ Kompetenceløft for personalet ☐ Andet (uddyb i kommentarer) ☐ Ved ikke
Kommentarer

Du satte x i "personale, specielt ansat mhp. den basale palliative indsats". Hvilket personale omhandler det? (sæt gerne flere x)

☐ Læger ☐ Plejepersonale ☐ Socialrådgivere ☐ Psykologer ☐ Præster ☐ Fysioterapeuter ☐ Ergoterapeuter ☐ Nøglepersoner med specifikt ansvar for den basale palliative indsats ☐ Eksterne konsulenter ☐ Andre (uddyb i kommentarer) ☐ Ved ikke
Kommentarer

Du satte x i "fysiske rammer for den basale palliative indsats". Hvilke rammer omhandler det? (sæt gerne flere x)

☐ Samtalerum ☐ Mulighed for enestuer ☐ Specielle sengeafsnit ☐ Specielle stuer til ambulante palliative funktioner ☐ Andet (uddyb i kommentarer) ☐ Ved ikke
Kommentarer

Du satte x i "kompetenceløft for personalet". Hvilke rammer for kompetenceløft omhandler det? (sæt gerne flere x)

☐ Tid ☐ Økonomi ☐ Undervisningslokaliteter ☐ Andet (uddyb i kommentarer) ☐ Ved ikke
Kommentarer

YLUA-RXME-8GL2

HOSPITALET'S REGISTRERING AF DEN BASALE PALLIATIVE INDSATS

I Danmark er den palliative indsats organiseret i:

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og

en basal indsats, som foregår på sygehusafdelinger, blandt praktiserende læger og på kommunalt niveau, hvor personalet ikke er specialuddannet, og hvor palliation kun er en delmængde af de opgaver, stedet skal løse.

Har hospitalet administrative værktøjer (f.eks. DRG) til registrering af den basale palliative indsats?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

Mangler hospitalet administrative værktøjer til registrering af den basale palliative indsats?

☐ Ja (uddyb i kommentarer) ☐ Nej ☐ Ved ikke

Kommentarer

YLUA-RXME-8GL2

Har sygehusledelsen ideer til administrative værktøjer til registrering af den basale palliative indsats?

☐ Ja (uddyb i kommentarer) ☐ Nej ☐ Ved ikke

Kommentarer

Har hospitalet administrative værktøjer (f.eks. DRG) til registrering af den specialiserede palliative indsats?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

Mangler hospitalet administrative værktøjer til registrering af den specialiserede palliative indsats?

☐ Ja (uddyb i kommentarer) ☐ Nej ☐ Ved ikke

Kommentarer

YLUA-RXME-8GL2

HOSPITALET'S INSTRUKSER OG RETNINGSLINIER

Har hospitalet etableret fælles instrukser/retningslinier for symptomlindring?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

Forventer sygehusledelsen, at hver afdeling selv etablerer disse instrukser/retningslinier for symptomlindring?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

Har hospitalet etableret fælles instrukser/retningslinier for den palliative indsats?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

YLUA-RXME-8GL2

Forventer sygehusledelsen, at hvert afdeling selv etablerer disse instrukser/retningslinier for den palliative indsats?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

Har hospitalet etableret fælles instrukser/retningslinier for omsorgen for pårørende til palliative patienter?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

Forventer sygehusledelsen, at hver afdeling selv etablerer disse instrukser/retningslinier for omsorgen for pårørende til palliative patienter?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

YLUA-RXME-8GL2

Kan hospitalets døende patienter tilbydes enestue?

☐ Ja, altid ☐ Ja, ofte ☐ Sjældent ☐ Nej, aldrig ☐ Ved ikke

Kommentarer

Har hospitalet en procedure for, at fælles instrukser/retningslinier implementeres i afdelingerne?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

Giv gerne 3 (ikke prioriterede) bud på, hvorledes hospitalets nuværende palliative indsats kan forbedres (må gerne omfatte både den specialiserede og den basale indsats):

1.

- 2.
- 3.

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Vil sygehusledelsen bakke op om PAVI's nationale kortlægning af den palliative indsats ved at komme med en opfordring til afdelingsledelserne om at besvare spørgeskemaet? (Ligesom her, bliver resultaterne håndteret fortroligt og fremlagt i anonymiseret form).

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

PAVI udarbejder gerne et udkast til opfordringen.

Du har svaret nej til at nogle af hospitalets ydelser kan betegnes som "palliativ indsats". Der er derfor ikke yderligere spørgsmål at besvare. Hvis du har kommentarer, er du velkommen til at skrive dem i kommentarfeltet herunder.

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Spørgeskemaet er slut, når du trykker på krydset nederst i højre hjørne (dette er vigtigt, da vi ellers ikke modtager din besvarelse).

Du skal have mange tak for din hjælp!

Med venlig hilsen
Palliativt Videncenter

Lene Jarlbæk, projektleder
lj@pavi.dk
3038 2349

Nikoline Nygård Knudsen, studentermedhjælp
nk@pavi.dk
3038 2302

Afsluttende kommentarer

National kortlægning af hospitalernes palliative indsats på basisniveau

Kære Afdelingsledelse

Dette spørgeskema henvender sig til lederne på alle danske hospitalsafdelinger, som har patientkontakt (og som ikke er palliative enheder/afdelinger).

Spørgeskemaet omhandler afdelingens målsætninger og organisering vedrørende den palliative indsats. Det omfatter både patienter med og uden kræft.

Skemaet bedes besvaret af en fra selve afdelingsledelsen. Respondenterne til de enkelte skemaer vil kun være kendt af Palliativt Videnscenter (PAVI). Svarene vil blive håndteret fortroligt og præsenteret i anonymiseret form.

Det tager ca. 15-20 minutter at besvare spørgeskemaet. Efterhånden som du udfylder spørgeskemaet, viser en bjælke nederst i billedet, hvor langt du er nået. Din besvarelse bliver først sendt til os, når du på sidste side trykker på krydset i nederste højre hjørne.

Undersøgelsen er udsprunget af den seneste tids forventninger/krav fra regionerne til sygehusledelserne om, at fokusere på den palliative indsats for alle patienter med livstruende, ikke forbigående sygdom (her kaldet palliative patienter). Skemaet indeholder 6 temaer ud over de indledende spørgsmål.

Hvis du har spørgsmål, er du velkommen til at kontakte Lene Jarlbæk (projektleder) på lj@pavi.dk eller tlf. 30382349.

Mange tak for din hjælp!

JSQV-S124-55EJ

INDLEDENDE SPØRGSMÅL

Sygehus

Afdelingens navn

Respondentens stilling

Respondentens kontaktdata (opbevares fortroligt, kun tilgængeligt for PAVI)

Email

Telefonnummer

Navn

JSQV-S124-55EJ

Den indsats, vi vil spørge til i det følgende, er WHO's definition af palliativ indsats:

Definition af palliativ indsats (WHO 2002)

Palliativ indsats er "at fremme livskvaliteten hos patienter og familier, som står over for de problemer, der er forbundet med livstruende sygdom, ved at forebygge og lindre lidelse gennem tidlig diagnosticering og umiddelbar vurdering og behandling af smerter og andre problemer af både fysisk, psykisk, psykosocial og åndelig art".

Har hospitalet en overordnet politik for den palliative indsats?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

Blandt jeres afdelings patient-klientel, kan I da komme ud for, at nogle af patienterne har en livstruende sygdom, som ikke er forbigående? (inkluderer også kroniske tilstande, hvor gradvis forværring kan medføre død)

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

JSQV-S124-55EJ

JERES AFDELINGS INVOLVERING I PALLIATION

I Danmark er den palliative indsats organiseret i:

en specialiseret indsats, som omfatter palliative teams, enheder, afdelinger og hospices, hvor

personalet er specialuddannet i palliation og kun beskæftiger sig med palliation
og

en **basal indsats**, som foregår på sygehusafdelinger, blandt praktiserende læger og på kommunalt niveau, hvor personalet ikke er specialuddannet, og hvor palliation kun er en delmængde af de opgaver, stedet skal løse.

Kan I, på jeres afdeling, komme ud for at skulle yde en palliativ indsats?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

Omfatter afdelingens palliative patienter

☐ Kun kræftpatienter ☐ Kun patienter uden kræft ☐ Både patienter med og uden kræft ☐ Ved ikke

Kommentarer

JSQV-S124-55EJ

Kan afdelingens involvering i palliative patientforløb omfatte

☐ Hele behandlingsforløb (fra diagnose til død) ☐ Perioder af behandlingsforløb ☐ Både hele og delvise forløb ☐ Kun enkeltstående ydelser (f.eks. behandling af fraktur, øjenundersøgelse osv.) ☐ Ved ikke

Kommentarer

Har afdelingen fokus på den palliative indsats?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

Hvem har sat fokus på afdelingens palliative indsats? (sæt gerne flere x)

☐ Afdelingsledelsen ☐ Sygehusledelsen ☐ Afdelingens læger ☐ Afdelingens plejepersonale ☐ En specialiseret funktion tilknyttet sygehuset (palliativt team eller lign.) ☐ En eller nogle få ildsjæle ☐ Andet (uddyb i kommentarer) ☐ Ved ikke

Kommentarer

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Har afdelingen en politik for den palliative indsats?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

Er politikken for den palliative indsats indført?

☐ Ja, den er indført ☐ Nej, den er ikke indført endnu ☐ Ved ikke

Kommentarer

Hvordan er politikken for den palliative indsats blevet kommunikeret i afdelingen?

☐ Mundtligt ☐ Skriftligt ☐ Både mundtligt og skriftligt ☐ Ved ikke

Kommentarer

JSQV-S124-55EJ

Hvilke palliative indsatser omfattes af politikken?

☐ Kun den basale indsats ☐ Kun den specialiserede indsats ☐ Både den basale og den specialiserede indsats ☐ Ved ikke

Kommentarer

Er politikken for den palliative indsats blevet evalueret?

☐ Ja ☐ Nej ☐ Ikke relevant ☐ Ved ikke

Kommentarer

Hvem har taget initiativ til at indføre politikken for palliation på afdelingen? (sæt gerne flere x)

☐ Afdelingsledelsen ☐ Sygehusledelsen ☐ Afdelingens læger ☐ Afdelingens plejepersonale ☐ En specialiseret funktion tilknyttet sygehuset (palliativt team eller lign.) ☐ En eller nogle få ildsjæle ☐ Andet (uddyb i kommentarer) ☐ Ved ikke

Kommentarer

JSQV-S124-55EJ

Hvornår er politikken for den palliative indsats indført? (skriv årstallet)

☐ Ved ikke

Kommentarer

AFDELINGENS RAMMER FOR DEN PALLIATIVE INDSATS

Har sygehusledelsen udstukket rammer for afdelingens palliative indsats? (med rammer menes omfang og/eller begrænsninger i vid forstand)

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

Er der i afdelingen blevet allokeret ressourcer specielt til palliation?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

JSQV-S124-55EJ

Hvilke ressourcer er blevet allokeret specielt til palliation? (sæt gerne flere x)

☐ Mere personale ☐ Udvidede fysiske rammer ☐ Kompetenceløft for personale, der beskæftiger sig med palliation ☐ Andet (uddyb i kommentarer) ☐ Ved ikke

Kommentarer

JSQV-S124-55EJ

Du satte x i "mere personale". Hvilket personale omhandler det? (sæt gerne flere x)

☐ Læger ☐ Sygeplejersker ☐ Social- og sundhedsassistenter ☐ Nøglepersoner med specifict ansvar for afdelingens palliative indsats ☐ Palliativ ambulatoriefunktion kun bemandet af læger ☐ Palliativ amulatoriefunktion kun bemandet af sygeplejersker ☐ Palliativ amulatoriefunktion bemandet af både læger og sygeplejersker ☐ Eksterne konsulenter ☐ Andre (uddyb i kommentarer) ☐ Ved ikke

Kommentarer

Du satte x i "udvidede fysiske rammer". Hvilke rammer omhandler det? (sæt gerne flere x)

☐ Samtalerum ☐ Mulighed for enestuer ☐ Specielle sengeafsnit ☐ Specielle stuer til ambulante palliative funktioner ☐ Andet (uddyb i kommentarer) ☐ Ved ikke

Kommentarer

JSQV-S124-55EJ

Du satte x i "kompetenceløft for personale, der beskæftiger sig med palliation".

Hvilke kompetenceløft omhandler det? (sæt gerne flere x)

☐ Fast, skemalagt undervisning ☐ Temadage ☐ Eksterne kurser ☐ Lejlighedsvis
undervisningssessioner ☐ Praktikperioder i specialiseret palliativ funktion ☐ Deltagelse i palliative
konferencer ☐ Andet (uddyb i kommentarer) ☐ Ved ikke
Kommentarer

Hvilke personalegrupper vedrører kompetenceløftet? (sæt gerne flere x)

☐ Læger ☐ Sygeplejersker ☐ Social- og sundhedsassistenter ☐ Sekretærer ☐ Andre (uddyb i
kommentarer) ☐ Ved ikke
Kommentarer

JSQV-S124-55EJ

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og

en **basal** indsats, som foregår på sygehusafdelinger, blandt praktiserende læger og på kommunalt
niveau, hvor personalet ikke er specialuddannet, og hvor palliation kun er en delmængde af de
opgaver, stedet skal løse.

Er det specialiserede niveau involveret i personalets kompetenceløft?

☐ Ja ☐ Nej ☐ Ved ikke ☐ Ikke relevant

Kommentarer

Hvorledes er den palliative indsats så etableret? (sæt gerne flere x)

☐ Ved omorganisering ☐ Ved at "løbe hurtigere" ☐ Ved frivilligt ekstraarbejde leveret af
personalet ☐ Ved besøg af frivillige ☐ Andet (uddyb i kommentarer)

Kommentarer

JSQV-S124-55EJ

AFDELINGENS OVERORDNEDE PRAKSIS OMKRING DEN PALLIATIVE INDSATS

Har afdelingen instrukser/retningslinier for symptomlindring?

☐ Ja ☐ Nej ☐ Ved ikke ☐ Ikke relevant

Kommentarer

Har afdelingen instrukser/retningslinier for den palliative indsats?

☐ Ja ☐ Nej ☐ Ved ikke ☐ Ikke relevant

Kommentarer

Anvendes Sundhedsstyrelsens "Faglige retningslinier for den palliative indsats" i afdelingen?

☐ Ja ☐ Nej ☐ Nej, er ikke bekendt med disse ☐ Ved ikke

Kommentarer

JSQV-S124-55EJ

AFDELINGENS DAGLIGE PRAKSIS OMKRING DEN PALLIATIVE PATIENT

Er det sædvane i afdelingen at forholde sig til om en patient "er palliativ"?

☐ Ja ☐ Nej ☐ Ved ikke ☐ Ikke relevant

Kommentarer

Definition af palliativ indsats (WHO 2002)

Palliativ indsats er "at fremme livskvaliteten hos patienter og familier, som står over for de problemer, der er forbundet med livstruende sygdom, ved at forebygge og lindre lidelse gennem tidlig diagnosticering og umiddelbar vurdering og behandling af smerter og andre problemer af både fysisk, psykisk, psykosocial og åndelig art".

Iværksættes rutinemæssigt en palliativ indsats, når en patient skønnes at være palliativ?

☐ Ja ☐ Nej ☐ Ved ikke ☐ Ikke relevant

Kommentarer

JSQV-S124-55EJ

Hvad består afdelingens palliative indsats til en patient af?

☐ Kun lindring af fysiske symptomer ☐ Overvejende lindring af fysiske symptomer ☐ Både lindring af fysiske symptomer og "andre problemer af psykisk, psykosocial og åndelig art" ☐ Kun lindring af "andre problemer" end fysiske symptomer (uddyb i kommentarer) ☐ Andet (uddyb i kommentarer) ☐ Ved ikke ☐ Ikke relevant
Kommentarer

Hvilke andre professionelle kan afdelingen tilbyde en palliativ patient bistand fra? (sæt gerne flere x)

☐ Psykolog ☐ Socialrådgiver ☐ Præst ☐ Fysioterapeut ☐ Ergoterapeut ☐ Andet (uddyb i kommentarer) ☐ Der er ingen mulighed for anden bistand (uddyb i kommentarer) ☐ Ikke relevant
Kommentarer

JSQV-S124-55EJ

I Danmark er den palliative indsats organiseret i:

en **specialiseret indsats**, som omfatter palliative teams, enheder, afdelinger og hospices, hvor personalet er specialuddannet i palliation og kun beskæftiger sig med palliation og

en **basal indsats**, som foregår på sygehusafdelinger, blandt praktiserende læger og på kommunalt niveau, hvor personalet ikke er specialuddannet, og hvor palliation kun er en delmængde af de opgaver, stedet skal løse.

Henviser afdelingen til en specialiseret palliativ indsats, når en patient skønnes palliativ?

☐ Ja, altid ☐ Ja, ofte ☐ Ja, indimellen ☐ Ja, sjældent ☐ Nej, for det er der ikke mulighed for ☐ Nej, aldrig ☐ Andet (uddyb i kommentarer) ☐ Ved ikke ☐ Ikke relevant
Kommentarer

JSQV-S124-55EJ

Har afdelingen mulighed for at konsultere det specialiserede niveau vedrørende en palliativ patient?

☐ Ja, i bestemte tidsrum på dagen ☐ Ja, på hverdage i almindelig dagarbejdstid ☐ Ja, alle ugens 7 dage i dagarbejdstid ☐ Ja, alle ugens 7 dage, døgnet rundt ☐ Nej ☐ Andet (uddyb i kommentarer) ☐ Ved ikke ☐ Ikke relevant
Kommentarer

Udskrives afdelingen terminalerklæring, når en patient skønnes palliativ?

☐ Ja, altid ☐ Ja, ofte ☐ Ja, indimellem ☐ Ja, sjældent ☐ Nej, aldrig ☐ Ved ikke

Kommentarer

Har afdelingen specielle rutiner, når en palliativ patient overflyttes til en anden hospitalsafdeling?

☐ Ja ☐ Nej ☐ Ved ikke ☐ Ikke relevant

Kommentarer

JSQV-S124-55EJ

Har afdelingen specielle rutiner, når en palliativ patient udskrives til hjemmet ("hjemmet" inkluderer også plejehjem, aflastningspladser o.lign.)

☐ Ja ☐ Nej ☐ Ved ikke ☐ Ikke relevant

Kommentarer

Hvilke specielle rutiner har afdelingen, når en palliativ patient udskrives til hjemmet? (sæt gerne flere x)

☐ Egen læge kontaktes så vidt muligt ☐ Egen læge kontaktes kun i helt specielle tilfælde ☐

Hjemmesygeplejen kontaktes altid ☐ Hjemmesygeplejen kontaktes ofte ☐ Pårørende kontaktes så vidt muligt ☐ Andet (uddyb i kommentarer) ☐ Ved ikke

Kommentarer

JSQV-S124-55EJ

AFDELINGENS PALLIATIVE INDSATS OMKRING PATIENTER, HVOR SNARLIG DØD KAN FORVENTES

Kan afdelingen tilbyde palliative patienter åbne indlæggelser?

☐ Ja ☐ Nej ☐ Ved ikke ☐ Ikke relevant

Kommentarer

Er antallet af åbne indlæggelser fastlagt?

☐ Ja, som et max antal pr. givent tidspunkt ☐ Ja, som et max antal hen over 1 mdr. ☐ Ja, som et max antal hen over 1 år ☐ Nej, antallet er ikke fastlagt ☐ Andet (uddyb i kommentarer) ☐ Ved ikke

Kommentarer

JSQV-S124-55EJ

Kan døende tilbydes enestue?

☐ Ja, altid ☐ Ja, ofte ☐ Ja, indimellem ☐ Ja, sjældent ☐ Nej, aldrig ☐ Ved ikke ☐ Ikke relevant

Kommentarer

JSQV-S124-55EJ

Definition af palliativ indsats (WHO 2002)

Palliativ indsats er "at fremme livskvaliteten hos patienter og familier, som står over for de problemer, der er forbundet med livstruende sygdom, ved at forebygge og lindre lidelse gennem tidlig diagnosticering og umiddelbar vurdering og behandling af smerter og andre problemer af både fysisk, psykisk, psykosocial og åndelig art".

Yder afdelingen en palliativ indsats til de pårørende til døende patienter?

☐ Ja, altid ☐ Ja, ofte ☐ Ja, indimellem ☐ Ja, sjældent ☐ Nej, aldrig ☐ Ved ikke ☐ Ikke relevant

Kommentarer

JSQV-S124-55EJ

Yder afdelingen en palliativ indsats til de efterladte til patienter, der er døde i afdelingen?

☐ Ja, altid ☐ Ja, ofte ☐ Ja, indimellem ☐ Ja, sjældent ☐ Nej, aldrig ☐ Ved ikke ☐ Ikke relevant

Kommentarer

ADMINISTRATIVE/ORGANISATORISKE EMNER OMKRING AFDELINGENS PALLIATIVE INDSATS

Registreres den palliative indsats på afdelingen?

☐ Ja ☐ Nej ☐ Ved ikke ☐ Ikke relevant for vores afdeling

Kommentarer

JSQV-S124-55EJ

Har afdelingen administrative procedurer til registrering af den palliative indsats?

☐ Ja ☐ Nej ☐ Andet (uddyb i kommentarer) ☐ Ved ikke ☐ Ikke relevant for vores afdeling

Kommentarer

Er de administrative procedurer til registrering af den palliative indsats tilstrækkelige?

☐ Ja ☐ Nej (uddyb i kommentarer) ☐ Ved ikke

Kommentarer

Er der behov for administrative procedurer til registrering af den palliative indsats på afdelingen?

☐ Ja (uddyb i kommentarer) ☐ Nej ☐ Ved ikke ☐ Ikke relevant for vores afdeling

Kommentarer

JSQV-S124-55EJ

Findes der DRG-koder til registrering af afdelingens palliative indsats?

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

Hvilke DRG-koder findes der?

Er afdelingsledelsen i dialog med sygehusledelsen om afdelingens palliative indsats?

☐ Ja, i tilfredsstillende omfang ☐ Ja, men ikke tilstrækkeligt ☐ Nej, der mangler dialog ☐ Nej, det er ikke nødvendigt ☐ Ved ikke ☐ Ikke relevant for vores afdeling

Kommentarer

JSQV-S124-55EJ

I forhold til de specialespecifikke, faglige ydelser, afdelingen forventes at varetage, er det så dit indtryk, at den palliative indsats fylder

☐ For meget ☐ Passende ☐ For lidt ☐ Ingenting ☐ Ved ikke ☐ Ikke relevant for vores afdeling

Kommentarer

Vil afdelingsledelsen bakke op om, at PAVI sender et spørgeskema til enkelte af afdelingens læger og plejepersonale som næste trin i "den nationale kortlægning af hospitalernes palliative indsats på basisniveau"? (Ligesom her, vil resultaterne blive håndteret fortroligt og fremlagt i anonymiseret

form.)

☐ Ja ☐ Nej ☐ Ved ikke

Kommentarer

Giv gerne 3 (ikke prioriterede) bud på, hvorledes afdelingens nuværende palliative indsats kan forbedres:

- 1.
- 2.
- 3.

JSQV-S124-55EJ

Du har svaret "nej" eller "ved ikke" til, at der blandt jeres afdelings patient-klientel kan forekomme patienter med livstruende, ikke forbigående, sygdom. Der er derfor ikke yderligere spørgsmål at besvare. Hvis du har kommentarer, er du velkommen til at skrive dem i kommentarfeltet herunder.

Du bedes trykke videre i spørgeskemaet for at afslutte det.

Du har svaret "nej" eller "ved ikke" til, at I på jeres afdeling kan komme ud for at skulle yde en palliativ indsats. Der er derfor ikke yderligere spørgsmål at besvare. Hvis du har kommentarer, er du velkommen til at skrive dem i kommentarfeltet herunder.

JSQV-S124-55EJ

Spørgeskemaet er slut, når du trykker videre i skemaet nederst i højre hjørne (dette er vigtigt, da vi ellers ikke modtager din besvarelse).

Du skal have mange tak for din hjælp!

Med venlig hilsen
Palliativt Videncenter

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Afsluttende kommentarer

Appendix 2: Observational frame from Spradley 1980 Page 82-83

	Space	Object	Act	Activity	Event	Time	Actor	Goal	Feeling
Space									
Object									
Act									
Activity									
Event									
Time									
Actor									
Goal									
Feeling									

Appendix 3: Respondents for the focusgroup- and individual interviews

Respondents	Type of interview	Newly qualified/ Experienced*	Department
Respondent 1	Individual	Experienced	A
Respondent 2	Individual	Experienced	A
Respondent 3	Individual	Experienced	A
Respondent 4	Individual	Newly qualified	A
Respondent 5	Focus	Experienced	C
Respondent 6	Focus	Experienced	C
Respondent 7	Focus	Newly qualified	C
Respondent 8	Focus	Experienced	C
Respondent 9	Focus	Experienced	C
Respondent 10	Focus	Experienced	C
Respondent 11	Focus	Experienced	B
Respondent 12	Focus	Experienced	B
Respondent 13	Focus	Experienced	B
Respondent 14	Focus	Newly qualified	B
Respondent 15	Focus	Experienced	B
Respondent 16	Focus	Experienced	B
Respondent 17	Focus	Experienced	B
Respondent 18	Focus	Experienced	B

*Nurses with more than two years' experience of the department were considered 'experienced' and nurses who had qualified within the previous six months were considered 'newly qualified'

Appendix 4: Interviewguide for focusgroup interviews

Fokusgruppeinterview.

- Velkomst
- Introduktion af moderator, sekretær og projekt.
- Kort intro af deltagerne
- Rammer for interview, skriftligt information, anonymitet.

Overordnet tema	Spørgsmål.
Begrebet palliation:	<p>Hvad forbinder I med begrebet palliation? (hvilke ord ville I bruge om det.)</p> <p>Hvilke palliative patienter har I her på afdelingen?</p> <p>Hvad er det der ”definerer” om en patient er palliativ? (Og evt. hvem?)</p> <p>Hvordan arbejder I med dette begreb her på Jeres afdeling?</p> <p>Hvad vil være god palliativ indsats på Jeres afdeling hvis I skal definere det? Eksempler?</p> <p>Eksempler på noget der ikke gik godt, eller kunne have været gået bedre?</p>
Retningslinjer:	<p>Arbejder I med retningslinjer/guidelines i arbejdet med palliation?</p> <ul style="list-style-type: none">- Hvilke?- Hvordan holdes afdeling ajour med disse?- Kender I SST's anbefalinger for den palliative basisindsats? Hvordan arbejdes med denne?- Kender I den gældende kliniske retningslinje? (Hvordan arbejdes med denne?)- Forslag til forbedringer i arbejdet/kendskabet til

	<p>retningslinjerne og guidelines?</p> <ul style="list-style-type: none"> - Hvordan vurderer I at Jeres kompetencer er i forhold til at arbejde med palliation? (er I klædt godt nok på? Hvad kunne være anderledes?)
Praksis i afdeling:	<p>Hvordan forholder I jer til om en patient er en palliativ?</p> <p>Hvilken indsats iværksættes når dette er tilfældet? (hvad gøres det helt konkret?)</p> <p>Hvordan arbejder I med forskellige faser i et palliativt forløb (hvis I opererer med forskellige faser)?</p> <p>Er der en tværfaglig indsats? På hvilken måde (hvilke faggrupper?)</p> <p>Hvordan samarbejder I med den specialiserede indsats (ex hospice, smerteteam)?</p> <p>Hvordan forgår samarbejdet med primær sektor i disse forløb?</p> <p>Hvordan arbejder I med at symptomlindre de palliative patienter. Her tænker jeg både:</p> <ul style="list-style-type: none"> - De fysiske - De psykosociale - De åndelige (talen om døden, religion, andet?) <p>Har I nogle ritualer eksempelvis når en patient dør?</p> <p>Gøres der noget særligt for at lave nogle fysiske rammer omkring disse patienter?</p> <p>Hvordan inddrager I de pårørende i de her palliative forløb?</p>
Organisering af indsats:	<p>Hvordan prioriteres den palliative indsats fra en ledelsesmæssig side? Er det overhovedet en prioritering? (Her tænker jeg både afdelingsledelsen og sygehusledelsen).</p> <p>Er indsatsen prioriteret nok? Eller hvor ser I den kan forbedres?</p> <p>Hvordan ser i at indsatsen organiseres fra ledelsesmæssig side? (oplever I at man har gjort sig nogle tanker omkring</p>

	<p>hvordan indsatsen organiseres? Ex. Nøglepersoner, ressourcer, uddannelse.)</p> <p>Er indsatsen organiseret godt nok? Eller hvor ser I at den kan forbedres?</p>
<p>Udfordringer/barrierer i for det palliative arbejde:</p>	<p>Hvilken udfordring ser I som den vigtigste/største i at arbejdet med at skabe rum for et godt palliativt forløb?</p> <p>Hvilke muligheder har I for at opfylde dette?</p> <p>Hvilke tiltag (interventioner) ser i ville kunne forbedre indsatsen?</p>

Andre kommentarer?

Appendix 5: Interviewguide for individual interviews

Individuelt interview.

- Velkomst
- Introduktion af projekt.
- Rammer for interview, skriftligt information, anonymitet.

Overordnet tema	Spørgsmål.
Begrebet palliation:	<p>Hvad forbinder du med begrebet palliation? (hvilke ord ville du bruge om det.)</p> <p>Hvilke palliative patienter har man her på afdelingen? Hvad er det der ”definerer” om en patient er palliativ? (Og evt. hvem?)</p> <p>Hvordan arbejdes med dette begreb her på Jeres afdeling?</p> <p>Hvad vil være god palliativ indsats på Jeres afdeling hvis du skal definere det? Eksempler?</p> <p>Eksempler på noget der ikke gik godt, eller kunne have været gået bedre?</p>
Retningslinjer:	<p>Arbejder I med retningslinjer/guidelines i arbejdet med palliation?</p> <ul style="list-style-type: none">- Hvilke?- Hvordan holdes afdeling ajour med disse?- Kender du SST’s anbefalinger for den palliative basisindsats? Hvordan arbejdes med denne?- Kender du den gældende kliniske retningslinje? (Hvordan arbejdes med denne?)- Forslag til forbedringer i arbejdet/kendskabet til

	<p>retningslinjerne og guidelines?</p> <ul style="list-style-type: none"> - Hvordan vurderer du at dine kompetencer er i forhold til at arbejde med palliation? (er du klædt godt nok på? Hvad kunne være anderledes?)
Praksis i afdeling:	<p>Hvordan forholder man sig på afdelingen til om en patient er en palliativ her på afdelingen?</p> <p>Hvilken indsats iværksættes når dette er tilfældet? (hvad gøres det helt konkret?)</p> <p>Hvordan arbejdes med forskellige faser i et palliativt forløb?</p> <p>Er der en tværfaglig indsats? På hvilken måde (hvilke faggrupper?)</p> <p>Hvordan samarbejdes med den specialiserede indsats (ex hospice, smerteteam)?</p> <p>Hvordan samarbejdes med stamafdelingen?</p> <p>Hvordan forgår samarbejdet med primær sektor i disse forløb?</p> <p>Hvordan arbejdes med at symptomlindre de palliative patienter. Her tænker jeg både:</p> <ul style="list-style-type: none"> - De fysiske - De psykosociale - De åndelige (talen om døden, religion, andet?) <p>Har I nogle ritualer eksempelvis når en patient dør? (information til øvrige patienter)</p> <p>Gøres der noget særligt for at lave nogle fysiske rammer omkring disse patienter?</p> <p>Hvordan inddrager du de pårørende i de her palliative forløb?</p>
Organisering af indsats:	<p>Hvordan prioriteres den palliative indsats fra en ledelsesmæssig side? Er det overhovedet en prioritering? (Her tænker jeg både afdelingsledelsen og</p>

	<p>sygehusledelsen).</p> <p>Er indsatsen prioriteret nok? Eller hvor ser du at den kan forbedres?</p> <p>Hvordan ser du, at indsatsen organiseres fra ledelsesmæssig side? (oplever I at man har gjort sig nogle tanker omkring hvordan indsatsen organiseres? Ex. Nøglepersoner, ressourcer, uddannelse.)</p> <p>Er indsatsen organiseret godt nok? Eller hvor ser du at den kan forbedres?</p>
<p>Udfordringer/barrierer i for det palliative arbejde:</p>	<p>Hvilken udfordring ser du som den vigtigste/største i at arbejdet med at skabe rum for et godt palliativt forløb?</p> <p>Hvilke muligheder har du for at opfylde dette?</p> <p>Hvilke tiltag (interventioner) ser du ville kunne forbedre indsatsen?</p>

Andre kommentarer?

Afslutning.

Appendix 6: – Information given to the departments prior to the observational study

Basal palliativ sygepleje på hospital. Et Ph.d. studium.

I forbindelse med mit ph.d. studie, som omhandler sygeplejerskers arbejde med palliation på sygehusafdelingen, vil jeg være at finde på afdelingen i ugerne XX og XX. Mit ærinde på afdelingen vil være at observere hvordan arbejdsgangen og forskellige rutiner finder sted, samt hvilken kultur der eksisterer omkring at have palliative patienter i en travl afdeling.

Palliation tænkes her meget bredt både fra den tidlige fase, hvor patienterne stadig er i behandling, til den terminale fase hvor patienten er døende.

Jeg er oprindelig uddannet sygeplejerske og startede efter min kandidatuddannelse (cand.scient.san) på mit ph.d.forløb i februar 2012. Jeg laver observationsstudier både på Sygehus 1, 2 og 3. Efter endt ph.d.forløb i 2015 vil mit studie udmunde i dels 3 publicerede videnskabelige artikler om mine resultater samt en ph.d.afhandling.

Jeg ser meget frem til at møde Jer alle. Har I spørgsmål eller kommentarer undervejs er I altid velkomne til at kontakte mig.

Mange hilsner fra Heidi Bergenholtz (hbz@regionsjaelland.dk)