

Building a Comparative Qualitative Evidence Base of Palliative Care (PC) within and across Countries

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Background

Global health organizations, such as the WHO (World Health Organization) and the WHPCA (World Health Palliative Care Alliance) and regional organizations like the EAPC (European Association of Palliative Care) and the APCA (African Palliative Care Association) have set up general goals for the development of palliative care (PC). These include, policy making, ensuring availability of services at all levels (including technology and drugs), education, research based documentation and funding. These general goals are dominant in the mapping of PC development globally. However, this could be viewed as a limited or reductionist understanding of PC development. We know that PC is being practiced and developed in communities and settings where it is not yet fully documented. This could be the case in home care settings in Denmark or in PC sites around the world. There is a common agreement, that more evidence on PC is needed. At the same time there is also agreement of recognising the cultural, social and economic context of each and every PC setting, community, country and region. This remains challenging and is very seldom achieved. The aim of this project is to take one step further forward in examining and comparing the quality and documentation of PC in different locations.



Meeting with partners in Dhaka, Bangladesh and Dakar, Senegal

Study Aim

The main purpose of this project is to contribute to a comparative qualitative evidence base for PC within and across countries, by:

1. Constructing an analytical framework for describing PC at a national but contextually relevant level
2. Exploring PC services and the perspective of people involved in them across different types of settings within and between different countries
3. Documenting locally based PC services

Methods

1. Descriptive analysis building on literature reviews, national documentation, interviews with stakeholders and a theoretical framework
2. Explorative studies using ethnographical methods; observations and interviews
3. A collaboration between researchers and professionals working within PC across countries

Initially the project will involve the following countries: Bangladesh in South-East Asia, Denmark in North Europe and Senegal in West Africa. . Other countries may be involved in the future.

Results

The study is in its first phase, searching for funding.

Part 1: A scoping review of PC in low and middle income countries showed that research based documentation (resulting in published peer review articles) from these countries is limited. Including the documentation from the countries in this project Bangladesh and Senegal. However, PC is widely practiced and development is ongoing. An analytical framework at an institutional level and inspired by the dimensions of “The welfare diamond” is suggested: The private health care market, the public health care system, the system of NGOs and volunteers and the system of families and social networks should all be described and analyzed as an overall frame for understanding the meaning of PC in a national context.

Part 2: Three projects have been proposed, but not yet funded: The first exploring PC in different settings in Denmark, one exploring PC in different settings in Senegal, and another describing both the concept and practice of “home-care” in Bangladesh and Denmark and exploring the experiences of old and frail immigrants and their carers from South-East Asia, living in Denmark.

Part 3: As a results of working together on PC documentation, an article on a 24/7 PC hotline in Bangladesh is ready for submission.

Perspectives

The perspectives for this project are to 1) elaborate on the concepts of quality and documentation of PC at both societal and organizational levels 2) to learn from one another through collaborations among individuals and settings involved in PC all over the world including all parts of their national health care systems.

