

# The Palliative Research Centre at Ersta Sköndal University College and Ersta Hospital in Stockholm

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A newly established Palliative Research Centre in Stockholm is presented. Firstly, we provide the background to the research conducted at the former department, which made the Centre possible. This is followed by a number of considerations regarding the development of the research programme. Finally, key features of forthcoming research are presented. We intend to continue to conduct further research into patients' and families' experiential and existential issues as well as the outcomes of palliative and supportive interventions related to the complexities of end of life, dying and bereavement. This will be complemented by practices and knowledge dissemination in professional palliative care teams as well as organisational and policy issues related to societal and population needs.

The Department of Palliative Care Research was established in 2007 at Ersta Sköndal University College and Ersta Diakonia in Stockholm in response to the need for enhanced knowledge and further development of palliative care to counterbalance inequity in patterns of care at the end of life. Through collaboration with the hospice clinic at Ersta Hospital, the Department was reorganised in 2012 into the Palliative Research Centre. Using earlier research as a foundation, this new dual partnership provides unique opportunities for further exploration, development,

testing and utilisation of clinically relevant knowledge. The Palliative Research Centre, like the former research department, is supported entirely through external funding.

The importance of establishing a research centre in this field can be related to the fact that internationally palliative care, and palliative medicine, as a discipline is a novel concept. In the UK, however, there are several successful palliative research centres. The first palliative research centre funded by the National Institute of Health in the

USA was established in 2007, resulting in substantial development in this field (Keenan et al., 2011). Furthermore, although Swedish research in this field has resulted in an impressive number of research articles and PhD theses with the potential for the results to interlink, there has been a lack of concentration and palliative research settings (SOU 2001:6; Swedish National Board of Health and Welfare, 2007). Fortunately, a national trend towards research collaboration, the development of stronger research facilities and efforts to perform multicentre studies is now emerging.

## Previous research enables future development

Researchers at the former department had a long tradition of research into dignity at the end of life in situations of dependency as well as promotion of identity, health and well-being from the point of view of patients, families and staff (Ternstedt et al., 2009). A major project "Importance of the home as the last place of care – ethics in the home and institutional sphere" was conducted during 2001-2009, and involved researchers from nursing, ethnology, philosophy, theology and ethics. The meaning of the concepts of autonomy, dignity, identity and home (e.g. Hellström, 2005; Dwyer, 2008; Karlsson, 2008, Österlind, 2009) became the foundation for some of the projects that are currently in progress. Studies have been carried out to examine experiences of a changed body, self-image or identity (e.g. Ekwall, 2009; Carlander, 2011) and dignity (e.g.

Dwyer, 2008). A model for person-centred palliative care – The 6 S – has also been developed (Ternstedt, 2009, Ternstedt et al., 2002, 2012).

Another line of research has focused on family support in palliative care (e.g. Andershed, 1998, 2006; Benzein & Saveman, 2008; Henriksson, 2012). Participation by family members in the care of a sick family member at the end of life has been developed conceptually (Andershed & Ternstedt, 1999, 2001) as well as development of interventions as part of palliative care aimed at supporting family members in the care process (Cronfalk, 2008; Cronfalk, et al., 2010; Henriksson, 2012). Further, such interventions have been tested (Benzein & Saveman, 2008; Henriksson, 2012).

Studies have been conducted with a focus on different care cultures, appropriate palliative care and experiences of personnel working with dying patients in advanced home care (e.g. Cronfalk, 2008; Carlander, 2011, Bergdahl, 2011) hospice care (Källström Karlsson, 2009), surgical care (James, 2010), nursing homes (Dwyer, 2008; Österlind, 2009; Söderlund et al., 2011), and basic home care (Ek, 2010; Wallerstedt, 2012). The care culture in advanced palliative care contexts seemed to be co-created by patient, family and staff. In nursing homes, discourse marked by silence regarding death and dying was characteristic (Österlind et al., 2011). Run in collaboration with Umeå University, 'Moral stress in care staff' is an on-going, multicentre intervention study at various nursing home units

for elderly people. The project is founded on extensive research into stress related to a guilty conscience within healthcare (Glasberg et al., 2006; Glasberg et al., 2008; Ericson-Lidman et al., 2012). The on-going intervention study is aimed at finding ways for staff to use conscious stress constructively so that it leads to an improvement in the care being provided instead of staff burn-out.

## Considerations for further development of the research programme

Looking back, we recognise that to some extent previous research followed a mainstream tendency in palliative care; targeting people with cancer (and their families) who are being cared for in specialised palliative care organisations. However, what is clearly noticeable is the inclusion of other diagnosis groups, such as elderly people at the end of life, who make up a large proportion of the population who are at the end of life. Today, we need to develop competencies and practices that take into account the complexities of advanced chronic and life-limiting conditions and prolonged end-of-life phases. In order to meet the needs of patients of any age, as well as their families, person- and family-centred palliative care become appropriate (cf. the definition of palliative care by the World Health Organisation).

Another characteristic of our research, also in the future, is the focus on people's well-being (cf. Haglund, 2010) and ways to promote their well-being

at the end of life.

In order to deepen and clarify meanings of well-being, we will theoretically and methodologically connect our research to the international concept of health-promoting palliative care; a focus on promotion of well-being and enhancement of quality of life for the part of the population who lives at the end of life.

According to Kellehar (1999), this approach is based on the premise that the social and spiritual aspects of palliative care are underdeveloped, in combination with an overemphasis on the physical and, to a lesser extent, psychological aspects. Furthermore, omitting public health components can be associated with a one-sided focus on the terminal phase, ignoring early phases of people's end-of-life illness trajectories. Considering that for many patients and families it takes time to make sense of receiving palliative treatments (e.g. Öhlén et al., 2012), late introduction of palliative care may limit the potential for severely ill people to choose how to live the time they have left. For family members, this is about having access to relevant support. Furthermore, there is a need for the development of health-promoting strategies and for implementation of palliative care knowledge at all healthcare system levels in society (Stjärnswärd et al., 2007). In addition, perspectives of health promotive palliative care are important in order to contribute knowledge of significance to change people's unequal access to palliative care.

It is worth considering that palliative care originates from certain philosophically founded principles that were developed several decades ago and that research in the field has expanded significantly during the last decade. The knowledge base for palliative care is accordingly composed of values, evidence and praxis. Thanks to recent research, there is the potential to critically reconsider established models and practices and develop empirically based practice principles. Innovative dissemination strategies for palliative care knowledge need to be developed and tested. In order to contribute knowledge of significance for the population – about quality of care at the end of life for example – the Swedish palliative register not only offers opportunities (Lundström et al., 2012) but also challenges the research designs that are being utilised.

## Key features of forthcoming research

Our intension for the Centre is to perform research that aims to be at the forefront in developing equitable, health-promoting palliative care research across all ages and different diseases, and independent of geographical location and places of care. Our research focuses on experiential and existential knowledge and outcomes of palliative and supportive interventions related to complexities associated with end of life, dying and bereavement. The research programme has two major research areas, both responding to palliative care needs among people across the whole life span: palliative

approaches for patients of all ages, and family and bereavement support. Palliative care for the elderly is an established field while palliative care for children is a new area under development. Tailored interventions will be undertaken for patients, families and significant others, as well as studies focusing on the intersection of gender, age, socioeconomic factors, illness conditions, places of care, aspects of palliative approaches, etcetera. Inquiries regarding the impact on patients, families and significant others will be complemented with the practices and knowledge dissemination of professional palliative care teams in society.

Within these focal areas and research areas, there are three kinds of knowledge interests that guide our endeavours. The first is an interest in conceptual clarification and elucidation of value conflicts, which encompasses critical understanding of models, theories and concepts on different levels of scope and abstraction. In addition, norms and values of significance to the understanding of palliative care require clarification. The second is an interest in scientific evidence for palliative and supportive interventions at the end of life and hence research-based, empirical knowledge of significance to patients and families. The third is an interest in dissemination and implementation of palliative care knowledge, which means a need for evidence of effective implementation strategies at different policy and organisation levels that are of significance to patients and families.

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