The Research Group investigating Person Centred Palliative Care – iPCPC / iPC²

Overall aim

This Gothenburg based group of multi-professional and interdisciplinary researchers collaborate on person centered palliative care with the aim to enhance patient and family outcomes in relation to diverse aspects of quality of life, collaborative decision making and end-of-life related transitions in the context of palliative care. We investigate in specialized as well as generic (integrated in diverse health care organizations) palliative care for adult and elderly people with diverse disease trajectories at the end-of-life independent of their medical diagnosis.

Our special focus is patients, significant others and providers as persons; palliative care simply demands a person focus, and has such a tradition since its origin half a century ago. In this way, person centred palliative care research offers special possibilities to contribute to the knowledge base of person centred care. Our research is both tailored for the special needs in Swedish health care and in the front line of international palliative care. It takes advantage of opportunity at the University of Gothenburg’s Person Centred Care Research Centre and its unique focus as well as collaboration with various palliative care practitioners. The ultimate goal is better palliative care practice.

Challenges in palliative care

The starting point for our research is a number of key characteristics in the field of current palliative care and related research. In Sweden, palliative care is unevenly developed which means people in need of palliative care have unequal access to palliative care services. Further, in Swedish palliative care we recognize a need to move evidence into practice, which require supporting knowledge translation and using innovative dissemination strategies. There is a need to support the education of health care providers in providing palliative care and at the same time increase public awareness of palliative and supportive interventions related to end-of-life care issues.

Swedish palliative care research has been characterized by small scale descriptive studies. In order to work collaboratively and conduct larger scale studies we need to:
- work in interdisciplinary research teams including collaboration with clinicians and international experts
- develop coordinated research that focuses on building programs of research (vs. Isolated studies)
- conduct research moving from description to intervention research and focus on patient outcomes.

Conceptual basis: Person Centred Palliative Care

Palliative care has developed practically and theoretically during the last half century. An essential component is person centred care and in palliative care patients, significant others as well as professionals are conceptualized as persons. For these reasons we build on palliative care philosophy, and expand with current person centred care theory. Essential features of patient as person in palliative care context are the patient’s identity, biography and family. Living a decaying and deteriorating body at the end-of-life often encompass both practical and existential issues, and experiential movements (e.g., from hope to hopelessness and wellbeing to distress).
Decreased personal autonomy and increased dependency on others in decision making is apparent. Being a significant other at the end-of-life occurs over a period of time – varying from days to years. However, it requires awareness of transitional nature of this period and subsequently handling transitions associated with this situation can be facilitated by special support. Person centred palliative care supports interest in various concepts such as deterioration of the body, symptom relieve, turning points and transitions, reconstruction of identity, anticipatory grief and bereavement. Specific palliative and supportive interventions that fit with person centred care include advance and end-of-life care planning, decision support and coaching, safety, providing communication aides and family empowerment.

Research themes

- **Person centred symptom relief in PC** – focus on symptom clusters; not disease specific symptoms; patient involvement in decision making about symptom management; supporting patients’ restorative activities to address symptoms
- **Person centered innovations in the organization and delivery of palliative care** – test person centred care interventions in different settings; focus on inter-professional care provided by teams; given changing demographics and expected increases in numbers of people requiring palliative care new ways of providing palliative care are needed
- **Person centred learning to enhance palliative care** – focus on information provision and communication in palliative care settings and the development of palliative care portals with potential to provide information to patients and families when they need it, and in a variety of forms e.g., including narratives, video stories, decision support aids, etc.

Types of designs

In person centred palliative care a variety of research designs are needed. We include longitudinal designs in order to contribute with knowledge of patients’ and significant others’ changing and varying needs over time. We consider the unpredictable future for patients in palliative care when designing clinical interventions. We often use mixed-methods designs combining deductive and inductive components, as well as qualitative and quantitative methods, in order to contribute with both pre-hypothesised outcomes and formative evaluation of interventions. We especially consider methodological developments needed to address influence of age, gender, socio-cultural aspects and their intersection. In order to develop feasibility of clinical interventions we include development and testing of new instruments and approaches to measurement, including how technological devices can support.

Significance

The practical and theoretical focus in palliative care on patients, significant others and professionals as persons means this programme of research on person centred palliative care will contribute to theoretical and practice improvements in palliative care and to the broader field of person centred care. Implementation and testing of person centred practices may be especially facilitated in palliative care contexts, and then further applied and validated in other health care contexts.
Investigating person centred palliative care is of special significance given the approaching demographic changes in society with a larger amount of elderly people living with palliative care needs over time. In order to contribute with significant knowledge, this group and its collaborative partners make possible to bring together expertise and resources to enable coordination of palliative care research including instruments and methods required for comparisons and multicenter studies. Further, this involves data bases of vulnerable groups at the end-of-life and across health care contexts.

The research group’s close collaboration with clinicians enhances implementation of both the research programme and research results.

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