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Opening the doors a crack wider: palliative care research data in the public domain

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ABSTRACT

This report builds further on OPCARE9, an EU 7th framework project aiming to identify knowledge gaps in care provision in the last days of life. This study began with curiosity about new ways of generating research questions to meet future challenges in palliative care (PC) and how to better engage disciplines not generally included in PC research. We here describe an innovative methodological approach to generating data; put data relevant for PC research in the public domain; and raise issues about open access in PC research. We aimed to compile research questions from different disciplines, based on raw data consisting of approximately 1000 descriptions of non-pharmacological caregiving activities (NPCAs), generated through previous research.

53 researchers from different fields were sent the full list of NPCAs and asked to generate research questions from their disciplinary perspective. Responses were received from 32 researchers from 9 countries, generating approximately 170 research topics, questions, reflections and ideas, from a wide variety of perspectives, which are presented here. Through these data, issues related to death and dying are addressed in several ways, in line with a new public health approach. By engaging a broader group of disciplines and facilitating availability of data in the public domain, we hope to stimulate more open dialogue about a wider variety of issues related to death and dying. We also introduce an innovative methodological approach to data generation, which resulted in a response rate at least equivalent to that in our Delphi survey of professionals in OPCARE9.

BACKGROUND AND AIMS

According to Tinetti,¹ death might be considered the most common of all ‘health events’. However, death is far more than a health event; it is an expected and unavoidable part of life,

inextricably interwoven with different underlying cultural norms. Death, dying and bereavement are also extraordinary, memorable and often difficult experiences for individuals and their families. Experiences related to end-of-life (EoL) care are thus major public health issues as everyone is affected by the deaths of others close to them as well as by their own mortality.

Palliative care (PC) has traditionally been defined by Cicely Saunders as intrinsically multidimensional in its attention to ‘total pain’,² that is, suffering and distress encompassing all forms of a person’s struggles when approaching death. Despite increasing recognition of and appreciation for the importance of non-pharmacological care, this multidisciplinary and transdisciplinary openness is not always fully represented in much PC research, which remains dominated by health professionals with pharmacological and specialist interventions and perspectives often highlighted. Even when addressing social, spiritual and practical issues, perspectives representing PC professional specialty services are often central.

Perspectives stemming from ‘new public health’ provide alternatives to this professional, specialty-based focus.³ New public health,⁴ inspired in part by the WHO’s Ottawa Charter for Health Promotion from 1986,⁵ explicitly involves communities in health promotion by enabling them to increase control over care through capacity building and empowerment. This community-based health promotion framework was initially applied to PC contexts by Kellehear and Sallnow.⁴ Our present work with ‘health-promoting PC’ has led us to increasingly recognise a need to re-conceptualise how

we conduct PC research if we are to begin to meet the challenges we are facing for the future. The need for new types of partnerships with various communities, including representatives of disciplines which have hitherto rarely been included in PC research, becomes clear when facing 'wicked problems', that is problems not readily fixed with discrete solutions, due to their changing, contradictory requirements and complex interdependencies.⁶ We also note that the trend towards open access, both in terms of publication of research results and in open access to databases, has had limited traction in much PC research to date. This professional protectionism may be understood to some extent as a function of our history, and the need to establish a position in the curatively oriented healthcare field; however, it may be time to reconsider different means of meeting the future of scholarship and care proactively.

The aims of this short report are therefore to make efforts in this direction by:

1. Describing an innovative methodological approach to generating data;
2. Putting data of potential relevance for PC research in the public domain;
3. Raising issues about how open access to knowledge might impact a PC paradigm and research.

METHODS

The data presented here derive from a follow-up study to a prior publication⁷ based on research conducted within OPCARE9, an EU 7th framework project aiming to identify knowledge gaps necessary to fill in order to optimise palliative cancer care provision in the last days of life. Systematic literature reviews and Delphi panels were generally employed as methods for this. Within an OPCARE9 work package on alleviating distress through pharmacological and non-pharmacological means, we instead used a variation of freelisting,^{8–10} an approach with roots in anthropology, to elicit descriptions of non-pharmacological caregiving activities (NPCAs) performed in specialised PC facilities in the nine OPCARE9 countries.

After Swedish pilot testing, a representative from each OPCARE9 country was asked to perform a brainstorming activity with at least one PC unit in his/her country, discussing which interventions and activities—besides administering medications—staff carried out with patients and families during the last days and hours of life. A first list of activities was generated, using spoken language, with descriptions in as much detail as possible. Staff was requested to add activities to the lists for 3–4 more weeks.⁷

The published results were based on inductive analysis of the variation found in the 914 statements about NPCAs generated from 16 specialised PC facilities in OPCARE9 countries in this manner. Given the nature of the generated NPCA data, with activities

often integrated and carried out simultaneously, prioritisation and ranking fundamental to a Delphi study were not judged meaningful. In a second phase, we instead made efforts to identify knowledge gaps by data sharing with a variety of experts to generate new research questions related to non-pharmacological care provision, in a manner we have not seen documented in the literature.

We contacted 53 senior researchers internationally active in different fields. The aim of this qualitative approach was to generate and compile research questions from different disciplinary perspectives, using the generated list of NPCAs as a basis for this. We sent out lists of the full data set of NPCAs, alphabetised by the first letter in the description of the activity. We requested that the researchers briefly browse the lists and formulate three research questions that quickly come to mind from their disciplinary perspective. All researchers were sent the same data, but the lists were sorted differently with regard to the letter beginning the alphabetised list. This was done to assure variety if researchers only examined the first few pages of the list.

ETHICAL CONSIDERATIONS

In all studies conducted through OPCARE9, ethical principles for research were followed in accordance with norms in each of the nine involved countries; whether formal ethical review was necessary or not varied by country. All staff contributing NPCA data were aware of the purpose of the study and agreed to contribute. The data collection via researchers was not necessary to subject to ethical review in Sweden, as the research issue was not sensitive, no personal information was provided, and the subjects were not in a dependent situation. However, all recipients of the invitation to participate were informed from the onset that the data generated would be published to provide a resource for all interested parties, and that publication would take place in a manner that prohibited a link to the individual respondent.

RESULTS

Responses were received from 32 researchers from nine countries, not identical with the OPCARE9 countries, who together generated approximately 170 research topics, questions, reflections and ideas. The respondents replied from the perspectives of palliative practitioners and researchers in behavioural science, medicine, nursing, occupational therapy and social work. Those without backgrounds in PC have expertise in anthropology, art, complementary and alternative therapies, ethics, IT sciences, medical history; yet others had backgrounds from social sciences and other healthcare fields. All the topics generated pertain to areas of potential interest for further research to benefit PC; these data are presented verbatim in online supplementary appendix 1.

DISCUSSION

Through this short report, we act on our commitment to address neglected issues related to death and dying as phenomena from both healthcare and non-healthcare perspectives in line with a new public health approach in several ways. By engaging a broader group of disciplines and facilitating availability of data in the public domain, we hope to stimulate more open dialogue about a wider variety of issues related to death and dying in a range of forums beyond those generally included in PC. We have also briefly described an innovative methodological approach to data generation, which resulted in a response rate at least equivalent to that achieved in our more traditional Delphi survey of professionals in OPCARE9.¹¹ The data presented here are, however, limited in that we make no claims as to which, if any, of the issues raised in the generated data have been addressed in prior research; nor have we evaluated the quality of the responses in any manner here. We fulfil our ambitions to stimulate variety in new research areas to fill knowledge gaps, rather than prioritisation as would have been the case had we used a Delphi panel.

Finally, we believe that inclusion of a broader range of professional and community competencies has much to offer PC for the future, in terms of improving care, improving research and incorporating knowledge exchange as a form for research dissemination. As open access to information increasingly gains credibility, we need to expand the types of impact we hope PC research may make. The home page of 'The open access week' claims: "Open access...has the power to transform the way research and scientific inquiry are conducted. It has direct and widespread implications for academia, medicine, science, industry, and for society as a whole."¹² As the Open Society also points out, open access "supports the unfettering of knowledge created through academic research both as an essential public good and as a way to address the gap between the production of academic knowledge and the needs of civil society."¹³ These goals are essential in our joint efforts to improve palliative and end-of-life care for broad populations.

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Collaborators The OPCARE9 team members in Sweden are: Carl-Johan Fürst (PI), Carina Lundh Hagelin, Olav Lindqvist, Gunilla Lundquist, Birgit H Rasmussen, Sylvia Sauter and Carol Tishelman.

Contributors All authors have contributed equally to the study design and data collection. OL and CT have contributed equally to drafting the manuscript which has been approved by all authors.

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REFERENCES

- 1 Tinetti ME. The retreat from advanced care planning. *JAMA* 2012;307:915–16.
- 2 Clark D. 'Total pain', disciplinary power and the body in the work of Cicely Saunders, 1958–1967. *Soc Sci Med* 1999;49:727–36.
- 3 Sallnow L, Tishelman C, Lindqvist O, *et al.* Research in public health and end of life care—Building on the past and developing the new. *Prog Palliat Care*. [In press].
- 4 Kellehear A, Sallnow L. Public health and palliative care: an historical overview. In: Sallnow L, Kumar S, Kellehear A, eds. *International perspectives on public health and palliative care*. New York: Routledge, 2012:1–12.
- 5 World Health Organization: The Ottawa Charter for Health Promotion. <http://www.who.int/healthpromotion/conferences/previous/ottawa/en/> (Last accessed 9 Nov 2015).
- 6 Periyakoil VS. Taming wicked problems in modern health care systems. *J Palliat Med* 2007;10:658–9.
- 7 Lindqvist O, Tishelman C, Hagelin CL, *et al.* Complexity in non-pharmacological caregiving activities at the end of life: an international qualitative study. *PLoS Med* 2012;9:e1001173.
- 8 Bernard HR. *Research methods in anthropology. Qualitative and quantitative approaches*. 3rd edn. New York: Altamira Press, 2002.
- 9 Tishelman C, Lövgren M, Broberger E, *et al.* Are the most distressing concerns of patients with inoperable lung cancer adequately assessed? A mixed-methods analysis. *J Clin Oncol* 2010;28:1942–9.
- 10 Weller SC, Romney AK. *Systematic data collection*. Newbury Park, CA: Sage Publication, 1988.
- 11 Lindqvist O, Lundquist G, Dickman A, *et al.* Four essential drugs needed for quality care of the dying: a Delphi-study based international expert consensus opinion. *J Palliat Med* 2013;16:38–43.
- 12 Open Access Week: About. <http://www.openaccessweek.org/page/about> (Last accessed 9 Nov 2015).
- 13 Open Society Foundations: Open Access Initiative. <http://www.opensocietyfoundations.org/grants/open-access-initiative> (Last accessed 9 Nov 2015).

Appendix 1: Verbatim research questions, ideas and issues generated from NPCA-list, listed and differentiated by individual respondent

- Optimal position for the bedridden patient? Lying flat as opposed to 15 and 30 degrees elevation of upper body in relation to oxygenation; subjective comfort (well-being, breathing, nausea and pain)?
- Prevention of decubiti at the end-of-life: Autonomy versus suffering from sores, gentle schedule for decubiti prevention?
- Death rattle: Who suffers—the patient, family and/or staff? How often can a patient express themselves with regard to suffering from ‘death rattle’? How often is a patient’s degree of consciousness so depressed that the possibility for suffering is eliminated? What effect does ‘recovery position’ have on minimizing death rattles?
- Thirst during the last days of life—analysis of causes: breathing through the mouth? Hyper-osmolality? Loss of large amounts of fluids? Evaluation of the effect of liquid in the mouth?
- That death is a process on all physical, psychological and emotional levels that can be investigated in regard to the old *Ars Moriendi*—the art of dying—tradition, that is (if not contagious) can be allowed to be drawn out and dialogic?
- Working on the assumption that the dying person has maintained all her senses, not least her skin – how can the need for sensory enjoyment/pleasure be satisfied?
- Investigations that structure family members’ need for both action and stillness, silence and conversation.
- What meaning does the level and type of function have for the experience of autonomy, and what impact does this have on existential well-being and coping (for example, what is the roll of different aids and appliances?)
- How is staff crying with patients experienced and interpreted? When is it seen as supportive, when is it frightening or distasteful? How does this differ by professional group?
- In terms of conflicts between patients and family members: Which conflicts should be avoided and which are important? How does staff deal with conflicts between patients and family members?
- What is a comfortable distance between a patient and health care staff, in particular in the patient-doctor relationship? What distance is ‘too distant’ in that it creates ‘emotional distance’ in a relationship? What is too close, in that it can be experienced as intrusive?
- Does everyone always want music? What kind of music? Do we know what different people appreciate? When is silence desirable instead?
- What parts of a patient’s body are appropriate to touch? How is this affected by cultural differences?
- General suggestion for broader research program: “Bodily contact, communication and integrity”
 - How can bodily contact facilitate communication? When does this have the opposite effect, i.e. an encroachment of privacy or integrity?
 - What is the extent of a patient’s ‘private sphere’? Does this change along the illness trajectory?
 - Is this different in different cultures?
- How can health care be better individualized? (people who die aren’t a homogenous group; need more focus on who the individual is)
- How can an environment be created which confirms the individual? When should one deviate from norms and dare allow individuality? (even if seemingly crazy)
- How do patients experience and deal with one’s deteriorating body? How does health care staff experience and deal with someone else’s deteriorating body? How do family members experience and deal with the deteriorating body of their relative?
- The here and now of palliative care: what is important to patients in the moment? (not only about planning for the future, inspired by statements about presence) What are patient’s and family’s desires in the moment, and how can we find these out? What is possible to desire? What do desires mean? What is most important—is there a need to rank desires, to

understand which desires really matter?

- How can more be done to empower family members?
- What does comfort mean in palliative care, in comparison with other phases in an illness trajectory, e.g. during chemotherapy treatment? (also related to thoughts about ‘the little extra’, e.g. warm towels after bathing)
 - What is comfort for family members spending time in palliative care facilities?
- Are there other types of materials than those commonly used in beds in palliative care settings (e.g. pillows, sheets, etc.) which might be better to use?
 - Can buckwheat pillows be a better alternative for comfort in palliative care than those pillows presently used? (more functional for supporting, better ability to form in accordance with the body, etc.)
 - (so many pillows in this material—need to do a pillow study!)
- How is the use of urinary catheters experienced at the end-of-life? (in general, treatments intruding past bodily boundaries) How is a non-functioning body experienced—that is when bodily functions are replaced by technical aids? What influences patients’ and family members’ acceptance of technologies that replace bodily functions?
- (Wound dressings) How can we best manage wound dressings in palliative care settings? Should we avoid burdening family members by involving them in care of such (sometimes repellant sores)? Is this ethically sound? Should we spare patients? Spare family members from the memory of such images?
- What meanings does ‘hope’ have for patients, family members and staff? How and when are these in agreement?
- What is an optimal environment in the last days of life, with regard to sound, light, air, etc.? E.g. the importance of having nice and clean surroundings, colors that match, aesthetics!!!
- How can gardens be brought to patients’ rooms, not only patients transported to gardens?
- How does staff think about and manage a patient’s dry mouth? Same question about other taken-for-granted bodily functions?
- How can technologies be better used to support patients and families cared for at home?
 - Which interventions/assessments should staff initiate instead of waiting for patient/family initiatives?
 - What can be done by telephone?
- What signs of discomfort can be distinguished by family and staff (not only body language, also color changes, etc.)?
- Where should the limits be for family involvement in care? How are these determined? How do family members experience carrying out patient care (e.g. brushing the teeth of an elderly mother, when you never have had that type of contact before)?
- Does family always want the health care staff to remain present? How do you know?
- What limits are there to appropriate touch? Touch by whom? Where can people be touched? How do we know?
- Important to talk about signs of ending-life! How can we teach people more about ‘how’ one dies in our society in which death is so absent? E.g. marble-like skin coloring
- Which technologies can be replaced by learning to observe other signs, e.g. thermometers? E.g. when urine production diminishes, how long will it take until the person dies?
- What are the views of physicians regarding non-pharmacological caregiving activities? Or the views of different professional groups towards the activities of other members of the team?
- How could all these listed activities be evaluated? Is it actually necessary to evaluate them?
- How can you research activities that are part of behaviour/expression of personal attitude?
- Is it already clear what the best ways for mouth care are?
- Caring for the dying body: How is comfort care experienced by dying patients? How do nurses decide what will be of comfort to their patients? What social constructions of comfort underpin how care is provided across different countries and cultures? Are there basic embodied expectations of comfort care that transcend cultures?

- How do nurses effectively care for the abject body? How do they assist family members to learn to care for the disintegrating body? How do staff prepare family members for the dying process?
- What does it mean to die in hospital? How do staff ascertain what 'home' means to dying people? How does hospital become a 'home' to die in? How do the preferences of individual nurses impact on the environment they create for the person to die in?
- What is the focus of care across different countries? Are there different caring narratives that inform culture-specific care practices within cultures and between cultures? What is the meaning of 'presencing' to different cultures? How are conflicting views about the dying process managed – patient to family; family to nurse; nurse to nurse; nurse to patient?
- What knowledge do patients' families have about the dying patient's situation, condition and needs? And what do they want to contribute in the situation?
- What does receiving help mean from the perspective of the dying person?
- Difficulties in the process of saying goodbye: How does one live with the knowledge that death is rapidly approaching for me? When is too early and when is too late to begin to talk about the process of saying goodbye (for both patient and family member)?
- A shame that nursing research deals so little with bodily well-being: eg. What does bodily well-being mean for different individuals? What can one ask for help with? What is impossible to ask for help with, since it is seen as taboo?
- How does a sick person feel when they have washed their hair/not washed their hair? How does bodily self-identity influence the experience of dignity? (How can we combine the bodily with the existential/spiritual?)
- How do we know what is most important for the family?
- Relationship between patient-staff: When is it hindered/facilitated by different needs, types of help, etc.?
- Who should be present at the time of death? Is it always the case that someone should be there? When is it better to be alone? Moment of death as a private occasion? How can staff be educated to be more sensitive to patient/family's desires?
- How is death dealt with in different cultures?
- What enables the staff to deal with the many different cultural ways of dealing with end of life? Do cultural differences present any problems when dealing with the patient and family members of the dying patient? Is cultural competence part of education and how does such education look in an increasingly multicultural Europe? How is difference made part of the routines in this area of care?
- Who takes care of the carers' emotions? How are they supported?
- For the Swedish part and I suppose in many other countries which have different levels of care where patients are referred to, what are the challenges in the patient chain of care? (particularly now when patients may be discharged from one level of care, say the hospital, for economic considerations, even when the needed competence to effectively care for the patient may be unavailable).
- How can violations of the patients' dignity, integrity and the right to die with dignity be researched and documented or are there are no such issues?
- The first thing I wanted to do is do a content analysis of all the comments, this would be useful in itself, as there are so many simple, but important suggestions that are easily overlooked. Many acts/behaviours are not new, but several are so simple in a sense that they may be overlooked.
- I was struck that palliative care really is a system in which family/friends and patients work together, patients and staff and family and staff. Again not new, but describing this system of care and comparing it with usual care in a sensitive manner may assist us in finding whether the care that evolves from being aware of these interconnections and building on them, results in outcomes/experiences that are more than the sum of its parts.
- Building on this a system can (should) also include the various care approaches or ways of connecting. There are already so many guides/brochures related to cancer care (CAM, information etc.) but how can we communicate to family, friends and care givers all those

simple thoughtful gestures and acts that mean so much at the end of life? Would posters help? Videos? Would they be more effective than brochures? Both? Further touch as well as massage and massage therapy seem to be very, very, common. There may have been studies in this population, but comparing the two (or three - depending on whether a difference is made between therapeutic and more generalized massage) as well as the combination may held understanding what is making the difference. It seems to me that the potential for touch related care/interventions is huge and inexpensive. The list also expanded on what personalized and/or holistic care is. Environmental factors such as smell, pets, air are known, but how can they be implemented such that we can measure its effects?

- How are existential needs, which can include but are not limited to established religious systems, be understood, assessed and addressed for each patient in the different countries?
- What constitutes the category of “difficult” patients in different countries and for the different caring team members?
- Are “cultural brokers” or other resource persons available when the caregiver and patient are operating within different cultural frameworks?
- What kinds of stress issues emerge for the different caring team members in the different countries?
- What kind of staff support is provided in the different countries?
- What are the policy(ies) and praxis in each country when family members want to prevent the patient from being told certain kinds of information?
- Are there gender-specific patterns, within and among the countries, in terms of patient requests for and/or staff delivery of massage and other bodily care routines?
- How do patients experience gentle massage at the end of life? And how do they react to different scents? I.e. are the senses more or less sensitive to touch and smell at the end of life?
- What information do families expect and appreciate from health care professionals when death comes closer to the patient?
- What is the effect of oxygen on nausea and pain at the end of life? Are these effects different if the patients are hypoxic or not?
- How do patients at the end of life reason about hope?
- What are the effects of team counselling or supervision on team members’ feelings of burnout and job satisfaction?
- How do dying patients experience being positioned vs. not being positioned, i.e. do they benefit from a turning schedule?
- What is the impact on family members’ well-being of follow-up after death of a significant relative?
- What characterises the signs of discomfort that professionals identify from dying patients – how do they define discomfort?
- How do professionals respond to the signs of discomfort that they identify from dying patients?
- What characterises the signs of comfort that professionals identify from dying patients – how do they define comfort?
- Frequency of visits and number of visitors per patient (non-professional visitors, e.g. friends, family etc.) in different palliative care settings (or of a certain PC setting compared to a non-PC setting, i.e. nursing home, geriatric ward)
- What do we (professionals/volunteers) sing and read with/to patients on their request (their choice)? without their request (our choice)?
- What are the topics staff/volunteers talk about with patients and/or family (plus time frame)?
- Enabling ‘self-care’ activities such as eating/drinking, dressing, washing etc. Research questions could address, in what ways or how are self-care activities of people in palliative stages of cancer enabled through activity guidance and assistive devices?
- Proving opportunity for enjoyment through activity. Research question should explore what activities are appropriate in terminal stages, i.e. cultural stimulation, creative engagement and also address the level of involvement the activities entail that can be on levels of sensory

involvement such as listening, watching and receiving or more active bodily involvement, social etc.

- Resting activity. This point concerns, how optimal resting can be supported through positioning and assistive materials when sitting, lying down and in 'light' activity.
- Social and environmental aspects. What are key factors for developing a soothing and stimulating environment, aesthetically as well as the physical (interior design, lighting, acoustics, among others) and social environment opportunities for being with or around others (minimizing experiences of being lonely- providing opportunity for family, socially important others)? In regard to social aspects it would also be important to explore aspects of generativity – possibilities for creating forms of legacy.
- How to support relatives and family so that they can play a caring role?
- How to support patients' existential needs?
- How to support patients' aesthetic needs?
- What is the nursing role in diagnosing dying?
- What is the meaning of comfort in palliative care?
- Exploring nursing therapeutic interventions in care of the body at end-of-life
- What is the importance of touch in palliative care nursing practice?
- How do we define optimal clinical nursing interventions for oral care at end-of-life?
- What does clinical presence mean in palliative care?
- What is the meaning of voice in end-of-life care?
- How do we create sleep-inducing environments?
- Clinical nursing assessment in the management of malodorous wounds
- What is the role of advocacy in palliative care nursing practice?
- The value of ethical comportment in clinical decision-making for palliative nursing practice?
- Anticipation in palliative care nursing practice – a pre-requisite for clinical expertise?
- What are the critical incidents which determine best practice in palliative nursing care?
- What kind of bathing is appreciated most by patients? What is it that bathing brings to patients? What are the benefits other than hygiene?
- Under what conditions do family members feel helped by assisting in the care of institutionalized patients? When is it felt to be a burden? To what extent do the desires of the patient and those of the family members concur?
- What kind of mouth care gives the patient most comfort? When is the balance between annoying and comfort the greatest?
- How can family members be helped to see the patient as dying and how can they be helped to be prepared to let him go?
- How can the nurse help family members to remain present?
- Are there identifiable factors that determine the frequency of mouth care that provides most comfort?
- Under what conditions can family members provide adequate comfort care?
- I would like to learn more about the influence of a dying person's favourite music on the process of dying.
- Referring to the following statement "Change to more masculine sheets than the flowered ones" I would like to know how far taking gender role stereotypes into account may influence the way of dying.
- Referring to the following statement "Give family time to spend with deceased" I would like to know what may be predictors to determine how much time I have to give the family for a "last good-bye".
- What is the dying trajectory of brain tumor (Glioma...) patients? What interventions - music, touch, talking, could make a difference in expressions of restlessness, discomfort..... of semi-conscious to unconscious patients?
- Comparative interventions for preventing and managing constipation in end stage patients

(morphine, bedridden...)?

- How can children and adolescents, who care for dying parents/siblings be best supported during the dying process and during the following 2 years?
- How can grandparents and ageing parents who care for dying children or grandchildren be best supported during the dying process and following the death?
- What learning experiences can support nursing students in overcoming their revulsion of the physical side effects of dying and their anxiety and fears about watching dying?
- How can we plan an environment for dying, which permits for comfort, privacy, cultural needs, as well as ready interventions for symptom relief (how to manage home versus other environments)?
- How can those, who have died many thousand times - perhaps years ago - , be comforted in their own dying (holocaust survivors, genocide survivors, war, rape.....)?

- Information to and education of relatives
- Information about the individual patient's preferences should be made available to the entire palliative care team

- Caregiving activities: something or anything that a care provider sees, evaluates, decides, does? That is, which are the sensory impressions, cognitive processes, and performance of activities in relation to dying patients? Which signals are registered? Are there differences between countries and professions in activities?

- Think also about family members versus the patient: how is the distribution in the list with regard to 'the whole family' versus family members and patients separately?

- That thought can also be relevant for teamwork versus individual activities. Are there patterns in this material with regard to that distribution?

- Now I've only read a few of the pages, which seemed to refer to activities that are directed to caring for staff rather than patients and families...e.g. *share my emotions with the team*, How would a research question about this be formulated? Don't think I can include it in this short brainstorming...

- I suggest that we ask family members to what extent the patient's death was congruent with how the patient would have wanted it to be, e.g. expectations, values.
- Several of the examples are about care for family members—that could be of great interest in order to see the extent to which patients' and family members' values are in agreement. An independent researcher should conduct this investigation, and maybe even compare with how the staff responds to the same question.

- How much should staff tolerate in terms of family members irrational and sometimes even insulting behavior?
- Where is the limit for staff's professional engagement and responsibility?
- What would shared decision-making look like with regard to the end-of-life? Autonomy versus doing 'good' for the patient from a professional perspective? Distribution of responsibility?
- Difficult feelings in response to a patient?...in this case, a sense of relief when a 'difficult patient' dies.
- Patients who treat their family members badly—what responsibility does staff have?

- What do palliative care staff do and what should they do to make the patient comfortable in terms of the patient's senses? This is a broad question and could be broken down to study each of the five senses. I was struck by the number of references to touch, hearing, smell. There were many references to touching the patient but do we teach staff how to do this? Do we have any evidence for how this works best?
- A similar question to be asked for their relatives. Is the need for perfume, for the relatives? Why does the window often get opened to let in fresh air?
- What is the relational experience both for the patient and the staff during provision of physical care? The same could be asked between the patient and the family carers.
- What is best done when the patient is restless?
- What does "support relatives" mean?
- What is the effect of staying with or being with the patient from the patient's point of view?

From the staff's point of view?

- What is done for the patient and their relatives when the patient is not responding? What is the perceived benefit of this?
- Investigate the impact of music therapy on quality of life in PC patients and their relatives.
- Are there special needs of homosexual PC patients compared to heterosexual? Does patients' sexual orientation influence professional care givers' end of life care and their attitude towards the patient?
- Impact of psychotherapy in end-of-life care: what are suitable methods, what are the needs, can they be met with standardized or individualized psychotherapeutic approaches?
- What nursing (or other health professional) interventions are interpreted by family members as facilitating their communication with their dying loved one in distinct palliative care contexts: (a) in general, b) when the patient is no longer conscious/responsive, and c) at the time of death and afterward)? (rationale: so many interventions aimed to model touching patient, engaging, using silences, murmuring words of comfort, explaining the physical signs associated with dying, bringing chairs close to the bedside etc. In order to understand when/how this is actually helpful and increased interaction is appropriate, it would be useful to gain family member perspectives of patterns and commonalities, as well as to document potential "downsides" to facilitating this communication (e.g. burden, distress)).
- How does the visual representation of the person at/following death influence the subsequent coping of those family members who attend at or following a death? (rationale: so many of the interventions seem to facilitate a tidy, calm, non-clinical environment, ensure that the personal grooming and physical positioning of the patient is attended to. These seem more oriented to the visual impression that will be the lasting legacy of the experience than to the specific needs of the patient. It would be important to explore whether the effects of this kind of intervention can be documented in terms of family bereavement – in contrast to, for example, a chaotic or grotesque last visual impression.)
- How are interventions aimed at easing the transition from palliative care context into the bereavement phase received/experienced by family members? (rationale: rapid disruption between the intensity of the caring environment and the next phase may complicate grieving/coping, and a number of interventions were aimed at easing this transition (e.g. having medical equipment removed from the home before the death, asking to phone a day later). It would be useful to document how they were perceived (how meaningful they were) from a family experiential perspective).
- How might experience prototyping be used in palliative care to allow carers, patient, and family alike to prepare for and facilitate *the experience of dying*?
- Might *ritual* beneficially punctuate *waiting* with meaningful final experiences/events? (e.g. from supplied notes: a patient being wheeled out late afternoon to feel the sunset with family – all were appreciative of this moment)
- What additional (cultural, philosophical, spiritual) tools/training can best prepare a carer to provide "nothing unnecessary" during these final days/hours?
- Apply local analgesia and wound dressing – In general wound care (cancer wounds) are an important area and especially analgesic treatment (systemic or local) needs further research as the pain conditions (partly neuropathic) can be difficult to treat.
- Accompany the patient after his request while starting sedation – If the statement points to palliative sedation I think much more research as well as ethical discussions are needed - especially in our part of the world.
- Advise the family about home care – In my country the home care function is scattered and when available the quality and content vary a great deal. We need a thorough survey of these matters - and indeed also from the family perspective.
- What are the advantages and disadvantages of having companion animals (pets) in hospices?
- What are the behaviours by health professionals and others health care workers that family members perceive to be most and least 'comforting' near the end of life?
- Appearance is believed to be important for most people in life but we know little about how physical appearance is 'managed' in the dying person. Yet physical changes to appearance are one of the most striking and memorable features of dying for the individual and their family

(e.g. wasting or oedema). Is attention to hair and personal hygiene important to the dying person and/or family members, and why?

- What care giving activities are indicative for 1) physical care giving; 2) psychological care giving; 3) social care giving; and 4) spiritual care giving at the end of life? And which activity cannot be ordered in one of these 4 domains?
- What is the proportion of different care giving activities spread over these four domains of care giving at the end of life?
- What proportion of different care giving activities oriented towards: a) the patient; b) the patient's family or next of kin; c) volunteers; d) professional care givers?
- Can Experience Design be used in palliative care to *customize* the "good death" for an individual, their family and loved ones?
- Can someone's *final cultural experiences* cause relief by triggering wanted memories, comfort, and normalcy for patient and family?
- What is the *dramaturgy* of a "good death?"

I have quickly read through the list. Coming from the Business Administration- and ICT (Author's Note: Information and Communication Technologies) field many different thoughts come into my mind. First and foremost, what is ICT about and how can it be put into play in situations as described in the list? Of course, it depends on how you look at ICT. Is ICT "just" the re-presentation of specifiable body parts, e.g. a bandage placed on a wound, or re-presentation of bodily parts, e.g. writing as extending the memory, etc., or is it something else, much more complex? Can "hold a hand" be exchangeable with ICT? I doubt it. From my point of view, technology is never the same thing as the human body (being) put into practice as in the shown examples. However, different ICT-solutions may be implemented as bio-representations (make the voice stronger (Skype for example), make the eyes stronger (video), (independent in time and space), etc. Saying that, thick empirical investigations will certainly show a lot of unpredictable results that will become evidence of the complexity of technology in practice and how it can be "used" in situations as shown in the list. Such research must go beyond looking at just instrumental consequences (effects), and incorporate researchers from different fields. There is so much to be done – as I see it – in this important field.