Measuring **quality of life and dignity** in palliative care research

Gwenda Albers

Measuring quality of life and dignity in palliative care research

The research presented in this thesis was conducted within the EMGO Institute for Health and Care Research, Department of Public and Occupational Health and of the VU University Medical Center, Amsterdam, The Netherlands. The EMGO+ Institute participates in the Netherlands School of Primary Care Research which was re-acknowledged in 2005 by the Royal Netherlands Academy of Arts and Sciences. In 2010 the EMGO+ Institute received an excellent review by the international external evaluation committee and of all Dutch university research, as organized by the universities in the Netherlands.

Financial support for the study projects included in this thesis were provided by:
- The Netherlands Organisation for Health Research and Development (ZonMw) – The Hague [grant no. 115 00 011]
- The project PRISMA, Reflecting the Positive Diversities of European Priorities for Research and Measurement in End-of-Life Care funded by the European Commission's Seventh Framework Programme [contract number: Health-F2-2008-201655]
- The Innovational Research Incentives Scheme VICI 2008 from the Netherlands Organisation for Scientific Research (NOW)

Financial support for the printing of this thesis was kindly provided by the VU University, the EMGO+ Institute and the Vrije Universiteit Brussel.

ISBN 978-90-8891-459-1

Lay out, cover design and photography: Maarten Uilenbroek || www.uilenbroek.com
Printed by: Proefschriftmaken.nl || Uitgeverij BOXPress

VRIJE UNIVERSITEIT

Measuring quality of life and dignity in palliative care research

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad Doctor aan
de Vrije Universiteit Amsterdam,
op gezag van de rector magnificus
prof.dr. L.M. Bouter,
in het openbaar te verdedigen
ten overstaan van de promotiecommissie
van de Faculteit der Geneeskunde
op maandag 15 oktober 2012 om 15.45 uur
in de aula van de universiteit,
De Boelelaan 1105

door

Gwenda Albers

geboren te Heemskerk

promotoren:	prof.dr. L.H.J. Deliens prof.dr. B.D. Onwuteaka-Philipsen prof.dr.ir. H.C.W. de Vet
copromotor:	dr. H.R.W. Pasman

Contents

Chapter 1

General introduction

Definition and history of palliative care

Palliative care finds its origin in the modern hospice movement led by Dame Cicely Saunders.[1,2] In 1967 Cicely Saunders founded the first professional hospice, St. Christopher's Hospice, in London. The hospice was founded on the principles of combining teaching, research and clinical care, seeking a balance between 'too much' and 'too little' treatment. By listening carefully to patients' stories of illness, disease and suffering the concept of 'total pain' was developed. Cicely Saunders coined the term 'total pain' to describe the multidimensional character of the palliative patient's pain experience including physical, social, emotional and spiritual aspects of suffering. The holistic approach to pain has become a new strategy in the care of dying patients.[1] The active total care for patients whose illness is chronic and who are in the last phase of life is nowadays defined as palliative care. Palliative care focuses on the control of pain and physical symptoms in addition to the social, emotional and even spiritual aspects of suffering, and is neither intended to prolong life nor hasten death, but to enhance quality of life.

In 2002, the World Health Organization (WHO) defined palliative care as: … *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.*[3]

The need for palliative care

The world's population is ageing. People are living longer and the proportion of people living to old and very old age is increasing.[4] In line with increasing life expectancy more and more people die from serious chronic diseases.[5,6] Chronic diseases such as cancer, cerebrovascular disease, heart disease and dementia tend to become more common with age. It might be expected that along with an increasing number of people living to older ages more people will live a relatively longer period of life with the effects of decline due to chronic diseases.[7,8] Older people reaching the end of life frequently suffer from more than one chronic condition. Multi-morbidity causes a wide range of physical, psychological and social problems, and, consequently, complex needs for care and support towards the end of life. As long-term care facilities such as nursing homes and homes for the elderly are increasingly settings where people live the last period of their life, long-term care facilities will also play an increasing role in the care of frail older people at the end of life. Projections of the ageing population show that more people will die from old age and/or complications due to end-stage chronic diseases emphasizing the importance of the availability of appropriate and effective palliative care to ensure people die with dignity.

Palliative care policy

Following the increasing and complex needs for care for people near the end of life, interest in palliative care has significantly increased in recent decades. An analysis by the Economist Intelligence Unit looked at access to services, quality of care and public awareness in 40 countries and found that the UK has led in terms of its hospice care and statutory involvement in end-of-life care. Other European countries including Denmark, Finland and Italy were found to lag a long way behind as the quality and availability of care is often poor and there is a lack of policy co-ordinations in these countries. In 2003, the European council approved a recommendation on palliative care that was adopted by the ministers of health in all 45 of the member countries; however, policy-making is mainly the responsibility of national governments in Europe.[9]

In the Netherlands, palliative care has become an important topic in the political agenda.[10] Several incentive programmes have been developed to improve palliative care, and to encourage education and training in palliative and end-of-life care.[11,12] An important step in the development of palliative care in the Netherlands was the policy programme 'Palliative care in the terminal phase' that the Ministry of Public Health assigned to 'ZorgOnderzoek Nederland' (ZON; in English: 'Health Research and Development Council').[13-15] This programme started in 1997 and aimed to develop palliative care in the context of already-existing institutions such as home care services, nursing homes and hospitals. Following on from the programme 'Centers for the development of palliative care" (COPZ's) were established which have significantly contributed to the expertise and increase in research activities in palliative care. Currently, palliative care is firmly on the public agenda and has become even more important for policy makers who organise and provide care. The state secretary for Health Well-being and Sports described palliative care as essential to the quality of life in the last phase of life and to ensure a dignified death.[10] As policy makers and health care professionals need to be provided with knowledge to develop policy and improve clinical practice, palliative care research is of great importance. The volume of research on end-of-life care, death and dying has grown considerably in recent decades and much progress has been made. However, end-of-life care research is still relatively new and faces many challenges.

Conceptual challenges in palliative care research

Conceptual clarity is a challenging factor in all research but particularly in a young and evolving research field such as palliative care. A great variety of operational definitions are found in research on this phase of life.[16,17] A disparity exists between conceptual and operational concepts of terminal illness and dying, and it is unclear what time period is meant by the end of life. Palliative care populations have been defined in various ways by researchers and policy makers.[17,18] Defining the scope of palliative care is of significant importance for research in this field, especially to enable the comparison of results across studies and countries. Borgstede et al describe the lack of clear population criteria as a consequence of the WHO-definition of palliative care which focuses on the goals of palliative care but is rather vague in describing the eligible population.[19] Palliative care is most commonly associated with people facing life-threatening illness and, consequently, much research on palliative care focuses on people with cancer. However, palliative care can also be applied to those with other chronic diseases such as heart failure, renal disease or neurodegenerative diseases such as multiple sclerosis or amyotrophic lateral sclerosis. Palliative care populations can be defined by the type of care provided in different health care settings e.g. hospice or palliative care unit. Patients can also be categorized as palliative care patients when receiving treatment that is not directed at cure or prolongation of life or when death is expected in the near future. In several randomized clinical trials investigators rely on the physician's prognosis about the last phase of life.[16,20,21] Conceptual differences as described above can be highly limiting with regard to generalizability, cross-study comparisons, research design and the selection of measurement instruments.[17]

Ethical challenges in palliative care research

In addition to conceptual challenges, end-of-life research creates some ethical challenges. Firstly, ethical questions arise when defining the risks and benefits of participation in a study.[22] This may become even more difficult as a patient's needs for care change substantially as they near the end of life.[23] In particular, randomizing terminally ill patients into two groups, one receiving a new intervention or therapy and the other receiving 'no treatment', standard therapy, or perhaps placebo, raises ethical difficulties.[24-26] This may become even more difficult as care needs change substantially towards the end of life. Second, research involves extensive and increased frequency of testing compared with standard clinical care while the goal of palliative care is to relieve suffering and improve comfort for patients and their families. Third, ethical concerns can be raised by the fact that the competence of patients near the end of life may be impaired. People can only give consent to participate in study if they are capable of understanding the information given by researchers. In addition, study participants must be competent to be able to decide at any time to withdraw from a study.[24-26] Especially for people facing a life threatening illness voluntary informed consent to participate in a research study may be difficult. These patients may be willing to try any treatment that might offer relief and may feel dependent on a research institute or investigator for their care. The vulnerability of patients near the end of life may influence their decision to participate in research projects.[27,28] A care provider's decision to ask a patient to participate in a research study may also be influenced by a patient's health condition. Care providers may believe that participating in a study may harm the patient. However, patients may be quite willing to participate and may see the benefit of interaction with a researcher or therapist, of making a contribution and of telling their story.[29]

Practical and methodological challenges in palliative care research

Research on end-of-life or palliative care is also characterized by several practical problems. A major practical issue in conducting prospective studies in general may be the characteristics and condition of the study population. The prospect of attrition due to early death is inevitable in end-of-life care studies, in addition to functional attrition, referring to the fact that palliative care patients are often unable to complete questionnaires or participate in interviews due to weakness, exhaustion or cognitive impairment.[17] However, randomized controlled trials have been considered as the gold standard for establishing robust evidence of the effects of a particular treatment or intervention as selection bias and confounding are avoided using this study design.[30-32] In general, because a patient's condition and evaluations can be followed over time or until the point of death, to study the process or trajectories of dying, prospective study designs are preferred over retrospective designs.[17,33] A challenge may be recruiting sufficient patients in the last phase of life to create a sample that is large enough. Recruitment often takes much more time than investigators have estimated. Lasagna's law described this phenomenon: at the time patient recruitment starts, the number of eligible patients becomes a fraction of what it was assumed to be before recruitment began. Investigators frequently depend on general practitioners (GPs) or other physicians to enrol patients into their study. However, GPs may tend to forget about the study or become less aware, due perhaps to the low prevalence of eligible patients or to time constraints.[34,35] Other reasons that eligible patients will not be recruited may be an unexpected rapid physical deterioration in the patient, a lack of skill and confidence in the physician or researcher in inviting them to take part, or the view that involvement would be too burdensome for the patient.[34] Moreover, at the time recruitment for end-of-life care studies starts, patients, especially those treated or residing in academic settings, may already be taking part in other research studies. In addition to the fact that terminally ill patients are rarely stable, the clinical heterogeneity regarding type of intervention, dose and duration of treatment, may limit end-of-life research and make any comparison and generalization extremely complicated. Another important methodological challenge includes the difficulty of determining appropriate outcomes and identifying measurement instruments to adequately assess those outcomes.

Palliative care research has frequently been associated with cancer patients and, consequently, not much research has investigated palliative care in long-term care facilities. However, palliative care can make an important contribution to improving the quality of life of older patients who suffer from multiple chronic diseases rather than cancer, though this may involve more challenges as there is a higher prevalence of cognitive impairment among older patients. As long-term care facilities are becoming more important in the provision of palliative care for those older people with multiple chronic diseases, part I of this thesis specifically focuses on the state of the art and the methodological rigour in palliative care research in long-term care facilities.

Measuring quality of life in palliative care

Over the past few decades, there has been a growing interest in the impact of health and health care on the quality of human life.[36] Not *quantity* of life but the improvement of *quality* of life has been increasingly used as an outcome in health care research. Currently, in numerous scientific studies outcome measurement plays an important role in order to observe changes in patients' subjective health status or to demonstrate improvement in quality of life which can be attributed to the effects of a specific intervention.[37] The European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Group developed one of the most widely used outcomes measures to assess health-related quality of life.[38] This questionnaire, the EORTC QLQ-C30, has been developed to assess physical and psychosocial symptoms and functioning in cancer patients. Several supplementary questionnaire modules have been developed to assess more specific issues relevant to particular types of cancer such as colorectal cancer, lung cancer and breast cancer. In addition, a shortened version of the EORTC QLQ-C30 was developed for use in palliative care patients, EORTC QLQ-C15-PAL.[39] Quality-of-life measurement is a fundamental aspect of palliative care because achieving the best quality of life for the patient and his or her family is the main purpose of palliative care. Most researchers and clinicians agree that quality of life is a multi-dimensional construct referring to a state of subjective wellbeing. However, the understanding of quality of life may be affected by several factors, such as the patient population, the setting, culture and whether the concept is used in research or clinical practice.[40] A consequence might be that quality of life has been approached in many different ways and that a great variety of measurement instruments has been developed and used in the last few decades. In addition, patients receiving palliative care are frequently not able to complete a questionnaire themselves and a proxy or health care professional will need to rate or assess the patient's quality of life.

Results obtained by instruments are used by researchers, health care professionals and policy-makers in order to develop further research, guidelines, evidence-based care and policy. Therefore the use of good or high-quality measurement instruments is of significant importance as these are able to provide more trustworthy results. First of all, in selecting a measurement instrument, a good content validity is one of the most important measurement properties of an outcome measure. Content validity refers to the degree to which the content of a measurement instrument is an adequate reflection of the construct to be measured.[41] Does a questionnaire developed to assess quality of life in terminally ill patients include all aspects relevant to these patients and are the aspects appropriate and sufficiently covered? In addition to a good content validity, a high-quality measurement instrument should measure what it is intended to measure, and all items in an instrument's scale or sub-scale should be internally consistent or, in other words, measure the same construct. The instrument should also be able to provide similar results on repeated measurements, and to detect changes over time.[41-44] A measurement instrument that meets all the aforementioned criteria can be considered as a high-quality instrument. Additionally, a measurement instrument needs to be appropriate and practically feasible for use in a particular study and setting.

Therefore, part II of this thesis aims to identify any existing instruments that might be able to assess quality of life in palliative care patients and to assess the content and clinimetric quality of these instruments.

Measuring dignity at the end of life

Palliative care is of great societal importance and growing attention has been paid to the perspective of the patient. Patients considering the end of life frequently mention the importance of preserving dignity. Dignity has been increasingly considered as a central goal in palliative care.

Dignity can be defined as the quality of being worthy of esteem or respect. A distinction can be made between two types of dignity: basic dignity and personal dignity. Basic dignity is the inherent dignity of every human being, which nothing can take away, and personal dignity refers to a personal sense of worth, associated with personal goals and social circumstances. It is related to a person's self-esteem and perception of being respected by others, and consequently it can be taken away or enhanced.[45,46] In this thesis we focus on personal dignity at the end of life.

The preservation of their dignity is mentioned frequently by patients when considering the end of life. Dignity is important to 92 per cent of the Dutch general public when asked what they consider important in their dying phase.[47] Disease and disabilities often elicit concerns about loss of dignity. In addition, loss of dignity is one of the most important reasons to formulate an advance directive in the Netherlands,[48] and one of the most common reasons for requesting euthanasia or physician-assisted suicide.[49-52] The law in Oregon concerning physician-assisted suicide is called 'the Oregon Death with Dignity Act'.[49] Understanding the causes of dignity-related distress could help to improve palliative care and research in palliative care. However, in order to make a concept measurable the concept first needs to be given theoretical meaning. In other words, to identify aspects that cause dignity-related distress at the end of life, conceptualization and operationalization of the concept of dignity is required. Dignity-related distress refers to suffering that can be caused by physical, psychosocial, spiritual, or existential issues, or as is often the case in terminally ill patients, some combination thereof.[53] Chochinov and colleagues developed an empirical model of dignity from a qualitative study to understand how dying cancer patients understand and define dignity.[54] As research involves empirically studying variables in order to describe and test hypotheses about the concept of interest, Chochinov and colleagues developed items from the themes and sub-themes in the model.[55] Subsequently, terminally ill cancer patients were asked how much they thought that these items could influence their sense of dignity. In this way the dignity model was validated and the Patient Dignity Inventory, a measurement instrument to detect end-of-life dignity-related distress, was developed.[56]

Dignity is comparable to the concept of quality of life with regard to breadth and level of abstraction. Compared to the number of studies that investigated quality of life, far fewer investigated the concept of dignity or used dignity as an outcome. Personal dignity goes beyond the assessment of physical and psychosocial health status and also includes perceptions of personal worthiness as well as worthiness in relation to others. In addition to quality of life, dignity can contribute importantly to palliative care research. Therefore, part III of this thesis focuses on further exploring the construct of personal dignity at the end of life as personal dignity.

Objectives and research questions of this thesis

This thesis consists of three parts, each with a different objective and different research questions.

The general objective of the first part is to provide insight into the research methodology in palliative care research in long-term care facilities. Most scientific studies on palliative care have been conducted with cancer patients; however, long-term care facilities are becoming more important in the provision of palliative care for older people. Therefore, part I specifically focuses on palliative care research in long-term care facilities. Accordingly, the research question addressed in Part I is as follows:

1. What is the methodological rigour of palliative care research in long-term care facilities in Europe?

The objective of the second part of this thesis is to explore the concept of quality of life in terminally ill patients and to evaluate quality-of-life measures suitable for use in palliative care. The main goal of palliative care is to improve the quality of life of the terminally ill patient, and therefore the measurement of quality of life plays an essential role in research in palliative care. Spiritual support is associated with better quality-of-life but the concept of spirituality is not well defined.[57] Therefore, another objective of part II is to investigate whether and how spirituality is operationalized in the quality-of-life instruments. The following research questions are addressed in part II of this thesis:

2. What are the most important quality-of life-domains for palliative care patients?

3. What is the content of and what are the domains measured by quality-of-life instruments that are suitable for use in palliative care?

4. How is the domain of spirituality operationalized in the quality-of-life instruments?

5. What is the feasibility and clinimetric quality of quality-of-life measures for use in palliative care?

The third part of this thesis focuses on personal dignity at the end of life. Dignity is increasingly considered as a goal of palliative care. The general objective of part III is to gain insight into the construct of personal dignity at the end of life, and to explore personal dignity as an outcome assessed by the Patient Dignity Inventory. The Patient Dignity Inventory is a measurement instrument that was originally developed to detect end-of-life dignity-related distress in terminally ill cancer patients.[56] The research questions addressed in Part III are:

6. What is the meaning of personal dignity at the end of life and can this be adequately measured with the Patient Dignity Inventory?

7. Does health status affect perceptions of factors influencing dignity at the end of life?

8. What are the perceptions of caregivers on factors influencing personal dignity in the terminally ill?

Methods

In order to answer the research questions different studies were performed. This section presents the main characteristics of these studies. The methods are described in more detail in the separate chapters of this thesis.

Systematic literature review on research methodology in palliative care research in long-term care facilities

In order to answer the first research question a systematic literature review was performed to find out what types of studies have been done with respect to the patient populations, study design and patient outcome measures on palliative care in long-term care facilities in Europe. PubMed, Embase and PsychINFO databases were searched from 2000 up to May 2010 by use of a search strategy including search terms related to 'palliative care' and 'end-of-life care' combined with search terms related to 'long-term care'. The search strategy yielded a total of 2825 hits of which 14 articles were included because they reported on patient outcome data of palliative care populations residing in a long-term care facility in Europe.

Literature reviews on quality of life

Two other literature reviews were conducted in order to answer research question 2 to 5. One to identify the domains that are most important for the quality of life of incurably ill patients and, one to identify instruments that can be used to measure these quality-of-life domains. For the first review, a nonsystematic search was performed in PubMed to find conceptual frameworks, indicators that are relevant for the evaluation of quality of life, and aspects that are important for the quality of life of palliative care patients. From the relevant studies that were found a framework that included the quality-of-life domains most important for incurable patients was developed. The other review was a systematic literature search in PubMed, Embase, CINAHL and PsycINFO databases to identify instruments measuring (at least one domain of) quality of life. This search yielded a total of 2015 hits. Finally, a total of 36 studies that described the development or validation of 29 instruments in a population of patients with no curative treatment options were included in the review. A checklist was used to describe the instruments' characteristics and, a rating list was used to evaluate the clinimetric quality of the instruments.

Survey study on dignity within the framework of a cohort study

The data used to answer research question 6 and 7 were collected within the framework of an advance directives cohort study. This cohort study is a major ongoing longitudinal study aiming to get insight into how advance directives are involved in end-of-life decisions in the Netherlands.[58] The data were collected by a structured questionnaire that was completed by 3812 participant of the cohort in the Spring of 2007. One half of the participants of the cohort completed the 22 items of the Patient Dignity Inventory[56] by indicating the extent to which they thought the items could influence their sense of dignity during the last phase of life. The other half of the cohort responded to an open-ended question on their definition of dignity and what issues would influence their sense of dignity during the last phase of life. The responses to the open-ended question were used to define the construct of dignity. The content validity of Patient Dignity Inventory was evaluated by assessing the relevance and comprehensiveness of the items of Patient Dignity Inventory by use of the COSMIN checklist (COnsensus-based Standards for the selection of health status Measurement INstruments).[59,60]

The data collected from the subsample of the advance directives cohort study that completed the Patient Dignity Inventory (n=2282) were used to study the effect of health status on the perceptions of factors influencing dignity at the end of life. This study sample was divided in three different health status groups (good, moderate, poor) based on a question on whether they had an illness and scores on the Euroqol-5D (EQ-5D) items. Descriptive statistics and logistic regression analyses were used to investigate the effect of health status on the perceptions of factors influencing personal dignity at the end of life, and the relationship between those perceptions and socio-demographic characteristics.

Survey study on dignity among caregivers

In order to answer the last research question another survey study was performed. Trained volunteers and end-of-life consultants (SCEN-physicians) were asked to indicate the extent to which they consider the items of the Patient Dignity Inventory can influence personal dignity in the last phase of life, and can make it problematic in practice to maintain personal dignity in the last phase of life. From the Fall of 2006 to January 2007 the survey questionnaire was completed by 236 volunteers and 427 physicians.

Outline of this thesis

The chapters of this thesis are based on articles that have been published in or submitted to a peer-reviewed scientific journal, and can be read independently.

Chapter 2 describes what types of studies on palliative care in long-term care facilities in Europe have been performed between the year 2000 and 2010.

Chapter 3 presents a quality-of-life framework and describes the content of and domains measured by quality-of-life instruments that are suitable for use in palliative care. In particular, there is a focus on how the domain of spirituality is operationalized in the instruments.

Chapter 4 provides an overview of the feasibility and clinimetric quality of all the quality-of-life instruments appropriate for use in palliative care is given.

Chapter 5 evaluates the construct of dignity and the content validity of the Patient Dignity Inventory in people with an advance directive in the Netherlands.

Chapter 6 describes how the perceptions of personal dignity at the end of life are related to health status, and other demographic factors.

Chapter 7 examines and compares how two different groups of care givers understand personal dignity in terminally ill patients.

Chapter 8 will discuss the main findings. In addition to some methodological considerations, implication for research policy and suggestions for further research will be considered in the final chapter of this thesis.

References

1. Clark D. 'Total pain', disciplinary power and the body in the work of Cicely Saunders, 1958-1967. Soc Sci Med 1999 Sep;49(6):727-36.
2. Phipps WE. The origin of hospices/hospitals. Death Stud 1988;12(2):91-9.
3. http://www.who.int/cancer/palliative/definition/en/.
4. Davies E, Higginson I.J., editors. Better Palliative Care for Older People. Geneva: World Health Organization, 2004 .
5. Davies E, Higginson IJ. The solid facts: Palliative Care. Copenhagen: World Health Organization; 2004.
6. WHO. Palliative care for older people: better practices. 2011.
7. Olshansky SJ, Rudberg MA, Carnes BA, Cassel CBJ. Trading off longer life for worsening health. Journal of Aging and Health 1991;3(2):194-216.
8. Verbrugge LM. Longer life but worsening health? Trends in health and mortality of middle-aged and older persons. Milbank Memorial Fund Quartely/Health and Society 1984;62(3):475-519.
9. The quality of death. Ranking end-of-life care across the world. A report from the Economist Intelligence Unit Commissioned by Lien Foundation; 2010.
10. Letter from Ministry of Health Well-being and Sports (2011). Verankering van palliatieve zorg in de praktijk. [Anchoring Palliative Care in Practice]. 2012.
11. http://www.zonmw.nl/nl/programmas/programma-detail/palliatieve-zorg/.
12. http://www.zonmw.nl/nl/programmas/programma-detail/verbeterprogramma-palliatieve-zorg/.
13. Ministry of Health Well-being and Sports. (1996) Palliatieve zorg in de terminale fase. [Palliative Care in the Terminal Phase].
14. Francke AL, Kerkstra A. Palliative care services in The Netherlands: a descriptive study. Patient Educ Couns 2000 Aug;41(1):23-33.
15. Gordijn B, Janssens R. Euthanasia and palliative care in The Netherlands: an analysis of the latest developments. Health Care Anal 2004 Sep;12(3):195-207.
16. Cook AM, Finlay IG, Butler-Keating RJ. Recruiting into palliative care trials: lessons learnt from a feasibility study. Palliat Med 2002 Mar;16(2):163-5.
17. George LK. Research design in end-of-life research: state of science. Gerontologist 2002 Oct;42 Spec No 3:86-98.
18. Lynn J, Harrell FE, Cohn F, Hamel M, Dawson N, Wu AW. Defining the "terminally ill": insights from SUPPORT. Duquesne Law Rev 1996;35(1):311-36.
19. Borgsteede SD, Deliens L, Francke AL, Stalman WA, Willems DL, van Eijk JT, et al. Defining the patient population: one of the problems for palliative care research. Palliat Med 2006 Mar;20(2):63-8.
20. Miller DK, Chibnall JT. Strategies for recruiting patients into randomized trials of palliative care. Palliat Med 2003 Sep;17(6):556-7.
21. Jordhoy MS, Kaasa S, Fayers P, Ovreness T, Underland G, hlner-Elmqvist M. Challenges in palliative care research; recruitment, attrition and compliance: experience from a randomized controlled trial. Palliat Med 1999 Jul;13(4):299-310.
22. http://www.wma.net/en/30publications/10policies/b3/index.html. 19-12-2011.

23. Casarett DJ, Karlawish JH. Are special ethical guidelines needed for palliative care research? J Pain Symptom Manage 2000 Aug;20(2):130-9.
24. Casarett D. Ethical considerations in end-of-life care and research. J Palliat Med 2005;8 Suppl 1:S148-S160.
25. Krouse RS, Rosenfeld KE, Grant M, Aziz N, Byock I, Sloan J, et al. Palliative care research: issues and opportunities. Cancer Epidemiol Biomarkers Prev 2004 Mar;13(3):337-9.
26. McWhinney IR, Bass MJ, Donner A. Evaluation of a palliative care service: problems and pitfalls. BMJ 1994 Nov 19;309(6965):1340-2.
27. Kristjanson LJ, Hanson EJ, Balneaves L. Research in palliative care populations: ethical issues. J Palliat Care 1994;10(3):10-5.
28. Roy DJ MNIDDHGMNe. Ethical issues in palliative care. Oxford texbook of palliative medicine. Oxford Universtiy Press, 1998:97-138.
29. Pleschberger S, Seymour JE, Payne S, Deschepper R, Onwuteaka-Philipsen BD, Rurup ML. Interviews on end-of-life care with older people: reflections on six european studies. Qual Health Res 2011 Nov;21(11):1588-600.
30. Muir Gray JA. Evidence-based healthcare. New York: Churchill Livingstone; 1997.
31. Mulrow CD, Oxman AD. Cochrane collaboration handbook. Oxford: The Cochrane Library, The Cochrane Collaboration; 1997.
32. Sackett DL, Richardson WS, Rosenberg W, Haynes RB. Evidence based medicine: how to practice and teach EBM. New York: Churchill Livingstone; 1997.
33. Thompson GN, Chochinov HM. Methodological challenges in measuring quality care at the end of life in the long-term care environment. J Pain Symptom Manage 2006 Oct;32(4):378-91.
34. Ruijs CD, Goedhart J, Kerkhof AJ, van der WG, Onwuteaka-Philipsen BD. Recruiting end-of-life cancer patients in the Netherlands for a study on suffering and euthanasia requests. Fam Pract 2011 Dec;28(6):689-95.
35. van der Wouden JC, Blankenstein AH, Huibers MJ, van der Windt DA, Stalman WA, Verhagen AP. Survey among 78 studies showed that Lasagna's law holds in Dutch primary care research. J Clin Epidemiol 2007 Aug;60(8):819-24.
36. Streiner D.L., Norman G.R. Health Measurement Scales. Oxford University Press; 2008.
37. Bausewein C, Daveson B, Benalia H, Simon ST, Higginson IJ. Outcome measurement in palliative care, The essentials. 2011.
38. Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. J Natl Cancer Inst 1993 Mar 3;85(5):365-76.
39. Groenvold M, Petersen MA, Aaronson NK, Arraras JI, Blazeby JM, Bottomley A, et al. The development of the EORTC QLQ-C15-PAL: a shortened questionnaire for cancer patients in palliative care. Eur J Cancer 2006 Jan;42(1):55-64.
40. Kaasa S. Assessment of quality of life in palliative care. J Palliat Med 2001;4(3):413-6.
41. Mokkink LB, Terwee CB, Knol DL, Stratford PW, Alonso J, Patrick DL, et al. The COSMIN checklist for evaluating the methodological quality of studies on measurement properties: a clarification of its content. BMC Med Res Methodol 2010;10:22.
42. Terwee CB, Dekker FW, Wiersinga WM, Prummel MF, Bossuyt PM. On assessing responsiveness of health-related quality of life instruments: guidelines for instrument evaluation. Qual Life Res 2003 Jun;12(4):349-62.
43. Kirshner B, Guyatt G. A methodological framework for assessing health indices. J Chronic Dis 1985;38(1):27-36.
44. Guyatt GH, Feeny DH, Patrick DL. Measuring health-related quality of life. Ann Intern Med 1993 Apr 15;118(8):622-9.
45. Pellegrino ED. Some things ought never be done: moral absolutes in clinical ethics. Theor Med Bioeth 2005;26(6):469-86.
46. Pullman D. Human dignity and the ethics and aesthetics of pain and suffering. Theor Med Bioeth 2002;23(1):75-94.
47. Rietjens JA, van der HA, Onwuteaka-Philipsen BD, van der Maas PJ, van der WG. Preferences of the Dutch general public for a good death and associations with attitudes towards end-of-life decision-making. Palliat Med 2006 Oct;20(7):685-92.
48. Van der Brugghen J, Rurup ML. "Ik wil dat mijn wil gerespecteerd wordt": Onderzoek naar de motivatie om een wilsverklaring op te stellen en de verwachtingen van mensen die recent een wilsverklaring hebben opgesteld. VU University Medical Center, Amsterdam; 2006.
49. Ganzini L, Nelson HD, Schmidt TA, Kraemer DF, Delorit MA, Lee MA. Physicians' experiences with the Oregon Death with Dignity Act. N Engl J Med 2000 Feb 24;342(8):557-63.
50. Haverkate I, Onwuteaka-Philipsen BD, van der HA, Kostense PJ, van der WG, Der Maas PJ. Refused and granted requests for euthanasia and assisted suicide in the Netherlands: interview study with structured questionnaire. BMJ 2000 Oct 7;321(7265):865-6.
51. Jansen-van der Weide MC, Onwuteaka-Philipsen BD, van der WG. Granted, undecided, withdrawn, and refused requests for euthanasia and physician-assisted suicide. Arch Intern Med 2005 Aug 8;165(15):1698-704.
52. Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. N Engl J Med 1998 Apr 23;338(17):1193-201.
53. Chochinov HM, Hassard T, McClement S, Hack T, Kristjanson LJ, Harlos M, et al. The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care. J Pain Symptom Manage 2008 Dec;36(6):559-71.
54. Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. Soc Sci Med 2002 Feb;54(3):433-43.
55. Michael S Lewis-Beck ABTFL. The Sage encyclopedia of social science research methods. 2011.
56. Chochinov HM, Krisjanson LJ, Hack TF, Hassard T, McClement S, Harlos M. Dignity in the terminally ill: revisited. J Palliat Med 2006 Jun;9(3):666-72.
57. Cohen SR, Mount BM, Tomas JJ, Mount LF. Existential well-being is an important determinant of quality of life. Evidence from the McGill Quality of Life Questionnaire. Cancer 1996 Feb 1;77(3):576-86.
58. Van Wijmen MPS, Rurup ML, Pasman HRW, Onwuteaka-Philipsen BD. Design of the Advance Directives Cohort: a study of end-life decision-making focusing on Advance Directives. BMC Public Health. 2010 Mar 26;10:166.

59. Mokkink LB, Terwee CB, Knol DL, Stratford PW, Alonso J, Patrick DL, et al. The COSMIN checklist for evaluating the methodological quality of studies on measurement properties: A clarification of its content. BMC Medical Research Methodology. 2010.
60. Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Stratford PW, et al. The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. Qual Life Res. 2010 May; 19(4): 539–549.

Part I

Research methodology in palliative care research in long-term care facilities

Chapter 2

What is the methodological rigour of palliative care research in long-term care facilities in Europe? A systematic review

Gwenda Albers, Richard Harding, H Roeline W Pasman, Bregje D Onwuteaka-Philipsen, Sue Hall, Franco Toscani, Miel W Ribbe, Luc Deliens, On behalf of PRISMA

Published in Palliative Medicine 2012, 26(5):722

Abstract

Background
The European population is rapidly ageing, resulting in increasing numbers of older people dying in long-term care facilities. There is an urgent need for palliative care in long-term care facilities.

Aim
The aim of this study was to systematically review the literature on palliative care research in long-term care facilities in Europe with respect to how the palliative care populations were described, and to determine the study designs and patient outcome measures utilized.

Methods
We used a systematic literature review. The search strategy included searches of PubMed, Embase and PsychINFO databases from 2000 up to May 2010, using search terms related to 'palliative care' and 'end-of-life care' combined with search terms related to 'long-term care'. We selected articles that reported studies on patient outcomedata of palliative care populations residing in a long-term care facility in Europe.

Results
This review demonstrated that there are few, and mainly descriptive, European studies on palliative care research in long-term care facilities. Fourteen studies were retained in the review, of which eight were conducted in the Netherlands. None of these studies described their study population specifically as a palliative care or end-of-life care population. Retrospective and prospective designs were applied using many different measurement instruments. Most instruments were proxy ratings. Symptom (management) was the most frequently measured outcome.

Conclusion
To improve future research on palliative care in long-term care facilities, agreement on what can be considered as palliative care in long-term care facilities and, the availability of well-developed and tested measurement instruments is needed to provide more evidence, and to make future research more comparable.

Background

The European population is rapidly ageing, characterized by a higher life expectancy and a decrease in birth rates in the European population.[1] The proportion of people living beyond age 60 will increase in most European countries to an estimated percentage of 25%–30% in 2020, and 30%–35% in 2050.[2] Gomes and Higginson demonstrated that people will die increasingly at older ages, and that the number of people dying at the age of 85 and over is expected to rise from 32% in 2003 to 44% in 2030 in England and Wales.[3] As Europe's population is ageing, the proportion of people living into very old age is increasing and these older people tend to die more often in long-term care facilities, such as care homes or nursing homes (NHs).[4] However, it is not just Europe that is facing the aging of their population, but also the USA, and even the populations of non-Western countries, and low- and middle-income countries are ageing.[5] Therefore, the provision of appropriate and effective palliative care to the growing number of older persons is an issue of great clinical and public health importance.[4] Moreover, it has been recognized that palliative care should be provided based on needs rather than prognosis or diagnosis.[6]

Long-term care facilities, such as NHs, are increasingly settings where people live their final period of life. In Belgium, the proportion of people who reach the end of their life whilst resident in a NH increased from 17% in 1998 to 21% in 2001.[7] In 2003 in Europe, there was a diverse range of death rates in NHs, which varied from 14% in Wales to 33% in the Netherlands.[8] The proportion of home deaths decreased overall from 31% in 1974 to 18% in 2003 in England and Wales, and decreased at an even higher rate for people aged 65 and over.[3] The projections for our ageing population emphasize the importance of organizing adequate palliative care to meet the needs of older people.

Palliative care is defined by the World Health Organization (WHO) as 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 physical, psychosocial and spiritual problems.[9] Palliative care for older people living in long-term care facilities should reflect their frailty and multiple problems and disabilities. A study from the UK demonstrated that the prevalence of dementia was 62% within long-term care institutions,[10] and most people in NHs and similar facilities die from multiple serious chronic diseases, and experience a complex trajectory of dying.[11]

Previous reviews on palliative care in NHs have focused on communication about end-of-life preferences, symptom assessment and factors influencing the provision of end-of-life care,[12] or identified empirical studies on end-of-life care in NHs in the US,[13] or focused on interventions and evidence regarding the impact of the interventions.[14] However, the current state of science in research in this population with respect to evidence for methodological design, measurement or outcomes has not been systematically appraised. Research among frail and very ill people must appropriately measure effects and outcomes in order to achieve quality improvement, to conduct needs assessment and to evaluate specific interventions.[15] In order to provide best quality evidence, to direct policy and practice for palliative care in long-term care facilities, it is essential to appraise the state of science to inform robust research, and to make recommendations for a collaborative research agenda to plan effectively for ageing populations.

A pan-European co-ordinating action, 'PRISMA', is focused on measurement and outcomes in order to inform best practice and harmonize research in end-of-life care across Europe.[16] Since many European countries are facing the need for effective palliative care in long-term care facilities, robust evidence to underpin public health policy and clinical practice is required. Therefore, one of the objectives of PRISMA is to identify and disseminate best practice in measurement in long-term care facilities, and to co-ordinate research activities in this field.

The aim of this study was to systematically review the literature on palliative care research in long-term care facilities in Europe with respect to how the palliative care populations were described, and to determine what study designs and patient outcome measures were utilized.

Methods

Search strategy

A search strategy to meet the study aims was derived. We searched PubMed, Embase and PsychINFO databases (2000–May 2010) using Ovid and the following search terms: palliative, terminal, end of life, advanced care, dying AND nursing homes, aged care, residential care/facilities, long-term care, assisted living facility, home for the aged, geriatric care/nursing/patient, elderly care, geriatrics, gerontology (medical subheading (MeSH) term or as a term that should be included in title/abstract) (see Appendix 1). The main search was supplemented by manual searches and consultation of experts.

The following criteria for the selection of studies were used: (1) the study should be a quantitative empirical research study; (2) the study should be on a palliative care population residing in long-term care facilities. For the purpose of this review studies on people diagnosed with a life-limiting incurable disease, as well as studies on frail and chronically ill people residing in a long-term care facility, were included. In addition, since the provision and structure of long-term care systems differ over countries, for the purpose of this study, a long-term care facility is defined as an institution providing nursing care 24 hours a day where mainly frail elder people are supposed to stay until death;[17]; (3) the study should report on patient outcome data in the domains of palliative care defined in the WHO definition of palliative care: pain and other physical, psychosocial and spiritual problems; (4) the study should be performed in one of the 27 countries included in the European Union or should be performed in Norway or Switzerland; and (5) in order to investigate the current state of science the study should have been published in English between 2000 and May 2010.

We excluded qualitative studies because this study is focused on outcome measurement. Studies performed in a non-European country or studies published as a case report, editorial, bibliography or reviews were also excluded. If there was any uncertainty about inclusion, eligibility was assessed by two reviewers (GA and RH) based on the full text of the article.

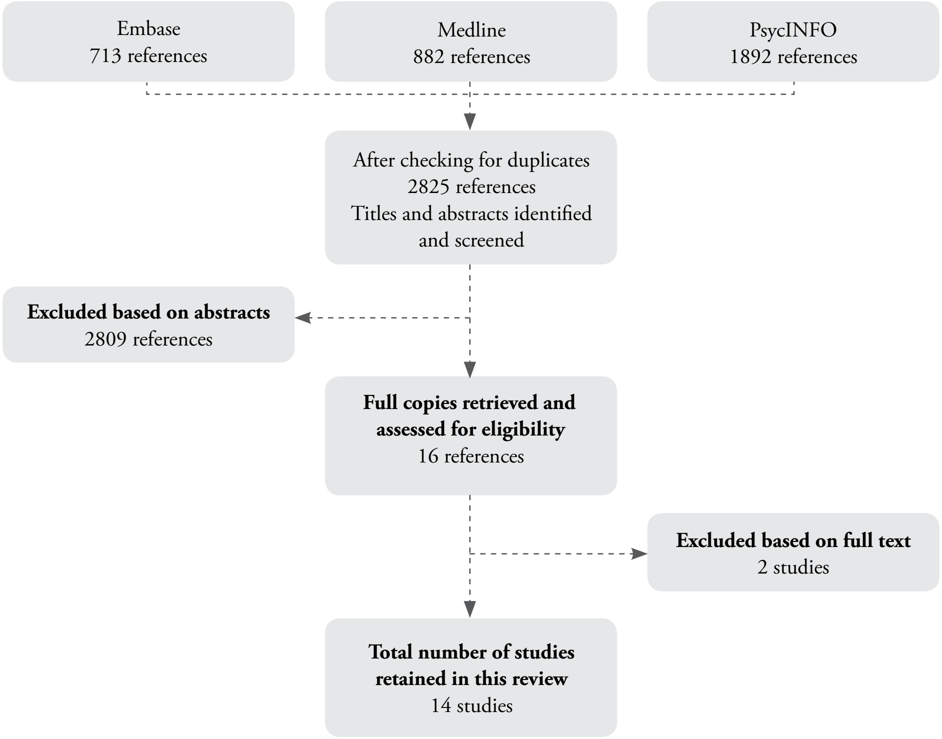
Data extraction and analysis

Data were extracted from the articles for the description of the palliative care population in a long-term care facility, the research method and design of the study, and the measurement instruments and outcomes used in the studies by one of the authors (GA). The results of the data extraction were checked by all authors, and any disagreements were discussed and resolved in a consensus meeting.

Results

The search strategy yielded a total of 2825 hits (Figure 1). The titles and abstracts were screened, and 2809 references were excluded in line with the inclusion and exclusion criteria described in the Methods section. Most of the excluded studies were qualitative studies, studies not performed in Europe or were not reporting on patient outcomes but on place of death, survival/readmission rates or on ethical aspects of palliative care in long-term care facilities. Of the 16 full-text articles we studied, two studies[18, 19] were excluded because they did not report on patient outcome data. Finally, a total of 14 studies were included in this review.

Figure 1 Results of Search Strategy



Most of the studies included in this review were conducted in the Netherlands and none described their study population specifically as a palliative care or end-of-life care population. Table 1 illustrates that four studies recruited patients living in a long-term care facility without any specific criteria.[20–23] Brandt et al.[11, 24] described the study population as terminally ill NH patients with a maximum life expectancy of six weeks, Van der Steen et al.[25] focused in one study on the last month of life of demented NH patients, two studies investigated cancer patients residing in long-term care facilities[26, 27] and six studies focused (partly) on dementia patients in long-term care facilities.[28–32]

Nine studies included in this review were prospective studies,[20, 22–24, 26, 27, 30–32] of which three studies were cross-sectional.[20, 22, 27] Five studies were retrospective,[11, 21, 25, 28, 29] of which three studies used information from death certificates,[21] chart reviews[29] or clinical records.[28] In addition, all studies included were descriptive studies, for example, prospective descriptive to examine the characteristics of care and quality of life during the last three days of life in NHs,[23] or cross sectional to investigate the prevalence and management of pain in newly admitted NH patients[20] or, for instance, retrospective to evaluate the presence of symptoms in the last two days of terminally ill NH patients.[11]

Table 1 shows that all but three studies[21, 22, 29] used at least one existing instrument to assess pain, physical and psychological symptoms, symptom management, health-related quality of life or discomfort. In addition, six studies[22, 25, 27, 28, 31, 32] assessed the cognitive status of the residents with the Mini-Mental State Examination (MMSE), the Functional Assessment Staging of Alzheimer's Disease (FAST) or the Bedford Alzheimer Nursing Severity scale (BAN-s). Outcome measures most frequently used in studies on palliative care in long-term care facilities included in this review were symptoms[11, 20, 23–25, 27, 29, 32] or symptom management.[25, 29] The Edmonton Symptom Assessment Scale (ESAS) and European Organization for Research and Treatment of Cancer Quality of Life Questionniare-C30 (EORTC QLQ-C30) were both used in two studies. Health-related quality of life was used as an outcome measure in only one study26 and was assessed with the EORTC QLQ-C30; discomfort or comfort in the dying phase was measured in three studies[25, 30, 31] using the Discomfort Scale for Dementia of the Alzheimer's Type (DS-DAT) and End-Of-Life Care in Dementia Comfort Assessment in Dying (EOLD CAD) scale; Brandt et al.[11] used a visual analogue scale (VAS) in one of their studies to assess the quality of death; one study used withholding or withdrawing artificial administration of food and fluids as an outcome measure;[21] one study used the presence of suicidal thoughts as an outcome measure.[22] Most of the instruments were used as proxy ratings; physicians, nurses or relatives completed them most frequently, and in only four studies data were collected from residents themselves.[20, 22, 26, 27] The different instruments contained different response scales, for instance, the ESAS and the Resident Assessment Instrument (RAI) contained a VAS, as the Nottingham Health Profile (NHP) is a yes/no questionnaire and the Palliative Care Outcome Scale (POS) and the EORTC QLQ-C30 are four-point scales.

Table 1 Published European Research on Palliative Care or End-of-Life Care in Long-term Care Facilities

Author, year, country	*Study population*	*Aim and study design*	*Outcomes measured*	*Measurement instruments*
Achterberg et al. 2007 [20] Netherlands	562 newly admitted NH* residents (representative sample of Dutch NH patients).	Prospective cross-sectional study to investigate prevalence and management of pain in newly admitted NH residents.	Pain (frequency and intensity) Perceived pain	- Minimum Data Set (MDS) 2.0 *based on observations of NH physicians at time of admission.* - Nottingham Health Profile (NHP) *answered by the patients read out by the NH physicians at time of admission.*
Brandt et al. 2005 [24] Netherlands	448 terminally ill NH patients with a life-expectancy of >6 weeks.	A prospective observational study to investigate quality of palliative care in terminally ill NH patients.	Quality of care (physical symptoms and psychosocial aspects)	- Palliative Care Outcome Scale (POS) (10-items; 5-point Likert scale) *completed on inclusion by NH physician and nurses and weekly by nurses.*
Brandt et al. 2006 [11] Netherlands	463 terminally ill NH patients with a life-expectancy of max. 6 weeks.	Retrospective evaluation of presence of symptoms in last 2 days of terminally ill NH patients.	Physical and psychosocial symptoms Physical symptoms/conditions Quality of death	- Edmonton Symptom Assessment Scale (ESAS) *completed by NH physicians 48-24 h and 24-0 h before death.* - Resident Assessment Instrument Minimum Data-Set Palliative Care (RAI MDS-PC) *completed by NH physicians 48-24 h and 24-0 h before death.* - Quality of death was rated on a VAS *by NH physicians and family members.*
Di Giulio et al. 2008 [28] Italy	141 severely demented elders in long-term care institutions.	Retrospective exploratory study. Data on symptoms, treatments, in last 48 h cardiopulmonary resuscitation attempts and life sustaining drugs, living wills and involvement of family in EoL decisions collected from clinical and nursing records.	Cognitive status	- Mini-Mental State Examination (MMSE)/ Functional Assessment Staging of Alzheimer's Disease (FAST) *data collected by clinical and nursing records.*
Jordhoy et al. 2003 [26] Norway	395 cancer patients died in NHs.	Prospective evaluation of characteristics of cancer patients who died in NHs.	Health related quality of life	- European Organization for Research and Treatment of Cancer Quality of Life Questionniare-C30 (EORTC QLQ-C30) *completed by the patients one month before death..*
Onwuteaka-Philipsen et al. 2001 [21] Netherlands	929 NH physicians.	Retrospective, death certificate study and survey among NH physicians to investigate incidence of withholding or withdrawing artificial administration of food and fluids (AAFF) and features of decision-making in deaths of a NH patients.	Withholding or withdrawing artificial administration of food and fluids	- Questionnaire to classify the end-of-life decisions *completed by NH physicians.*
Pautex et al. 2003 [27] Switzerland	42 elderly cognitively intact cancer patients residing in geriatric hospital with longstanding palliative care specificity.	Prospective cross-sectional survey to examine concordance of symptom assessment between cancer patient, nurse and physician.	Cognitive status Physical and psychosocial symptoms	- MMSE *administered by trained physicians.* - ESAS *completed by patients, nurses and physicians.*

Author, year, country	*Study population*	*Aim and study design*	*Outcomes measured*	*Measurement instruments*
Pautex et al. 2007 [29] Switzerland	50 patients with and 50 patients without dementia hospitalized in geriatric hospital with longstanding palliative care specificity.	Retrospective chart review to identify differences in type of end-of-life care between patients with and without dementia.	Symptom management	
Scocco et al. 2009 [22] Italy	Random sample of 172 individuals aged 65< living in NHs.	Prospective cross-sectional survey to evaluate prevalence of death- and/or suicidal feelings/thoughts/plans and attempted suicides in NH residents.	Cognitive status Presence of suicidal thoughts/plans;	- MMSE *administered by research assistant..* - 5 questions on the presence of suicidal phenomena originally proposed by Paykel et al. *read out by research assistant*.
Van der Steen et al. 2009 [25] Netherlands	Nurses and family caregivers involved in last months of life of 48 NH residents.	Retrospective study to investigate correspondence between symptoms and comfort ratings in dementia patients at the end of life rated by nurses and families.	Alzheimer status Symptom management Comfort assessment in dying	- Bedford Alzheimer Nursing Severity scale (BANS-s) *completed by nurses 3 months before death.* - End-Of-Life care in Dementia Symptom Management scale (EOLD SM). - End-Of-Life care in Dementia Comfort Assessment in Dying (EOLD CAD) scale *completed by family members 2 months after death and nurses 2 months-1 year after death in face-to-face interview with the investigator.*
Van der Steen et al. 2004 [32] Netherlands	61 Dutch NH patients with dementia and lower respiratory tract infection.	Two prospective cohort studies to compare treatment of NH residents with dementia and lower respiratory tract infection (pneumonia) in the US and the Netherlands.	Alzheimer status Symptoms and signs of lower respiratory tract infection	- BANS-s *completed 3 months before death by NH physicians.*
Van der Steen et al. 2002 [31] Netherlands	374 demented NH patients treated with antibiotics for pneumonia.	Prospective cohort study to assess the relationship of the dementia severity to outcomes of pneumonia.	Discomfort Alzheimer status	- Discomfort Scale for Dementia of the Alzheimer's Type (DS-DAT) *completed by NH physicians.* - BANS-s *completed by NH physicians.*
Van der Steen et al. 2009 [30] Netherlands	725 demented NH patients.	Two prospective studies to assess associations between discomfort and dying from pneumonia and prolonged intake problems.	Discomfort	- DS-DAT *completed by NH physicians.*
Veerbeek et al. 2007 [23] Netherlands	102 patients who died in a nursing home setting.	Prospective study described the characteristics of care and quality of life during last 3 days of life in 3 different settings.	Burden of symptoms Communication aspects	- A part of EORTC QLQ-C30 *completed by nurses and relatives 1 week after patients death.*

*NH: nursing home

Table 2 shows the domains of the WHO definition of palliative care that were measured by the instruments. The physical domain was measured by most of the instruments. All instruments included items on pain except for the DS-DAT, which is an observational instrument used to measure discomfort in severely affected Alzheimer patients. Achterberg et al.[20] used only the two pain items of the Minimum Data Set (MDS) in their study and the NHP, which just focuses on pain. All other instruments included in Table 2 contain items on other physical problems, and six of these also contained items on psychological items, and just the POS contained, in addition to items on pain, other physical problems and psychological problems and items on spiritual problems. Shortness of breath is most frequently contained by the instruments used in the studies included in this review regarding physical problems other than pain. With regard to psychological problems, items on depression and anxiety are the most frequently contained in the instruments.

Table 2 Instruments and the Domains of the WHO Definition of Palliative Care Measured

	Pain	*Other physical problems*		*Psychosocial problems*		*Spiritual problems*	
MDS*	x						
NHP	x						
POS	x			x	Anxiety/worried	x	Feeling about worthwhileness of life, Feeling about yourself as a person
ESAS	x	x	Activity, Nausea, Appetite, Shortness of breath, Drowsiness	x	Depression, Anxiety, Well-being		
RAI	x	x	Difficulty with coughing, Shortness of breath at rest, Shortness of breath with exertion, Constipation, Diarrhea, Dry mouth, Fecal Impaction, Nausea/vomiting, Anorexia, Change in sleep pattern, Change in usual sleep pattern, Tired easily, Fever, Impaired endurance, Infections, Skin condition, Nutritional intake, Nutritional state; (Items added in Brandt et al. study: Death rattle, Fatigue, Confusion, Pressure ulcer)				
EORTC QLQ-C30	x	x	ADL, Mobility, Shortness of breath, Tiredness, Sleeping problems, Weakness, Appetite, Nausea, Vomiting, Constipation, Diarrhea, Difficulty with remembering things, Overall perceived health and quality of life (Items added in Veerbeek et al. study: Agitation, Fear, Confusion, Confusion, Incontinence, Troublesome mucus production)	x	Tense, Irritated, Depressed, Worries, Interference of family life and social activities		
EODL-SM	x	x	Shortness of breath, Agitation, Calm, Skin breakdown	x	Depression, Fear, Anxiety, Resistance to care		
EODL-CAD	x	x	Discomfort, Restlessness, Shortness of breath, Choking, Gurgling, Difficulty in swallowing	x	Fear, Anxiety, Crying, Moaning, Serenity, Peace, and Calm		
DS-DAT		x	Noisy breathing, Negative vocalization, Content facial expression, Frown	x	Sad facial expression, Frightened facial expression, Relaxed body language, Fidgeting		

* Achterberg et al.[20] just used the pain items of the MDS.
MDS: Minimum Data Set, NHP: Nottingham Health Profile, POS: Palliative Care Outcome Scale, ESAS: Edmonton Symptom Assessment Scale, RAI: Resident Assessment Instrument, EORTC QLQ-C30: European Organization for Research and Treatment of Cancer Quality of Life Questionniare-C30, EOLD SM: End-Of-Life care in Dementia Symptom Management scale, EOLD CAD: End-Of-Life Care in Dementia Comfort Assessment in Dying scale, DS-DAT: Discomfort Scale for Dementia of the Alzheimer's Type, ADL: activities of daily living.

Discussion

This review identified 14 studies reporting on patient outcome data collected in long-term care facilities in Europe published after the year 2000. The majority of the studies included in this review are performed in the Netherlands, and most did not describe the study population as terminally ill or specifically as a palliative care or end-of-life care population. All studies were descriptive rather than evaluative studies. Symptoms, especially pain, were the most frequently measured outcomes, and many different measurement instruments were used to collect patient outcome data.

Palliative care in long-term care facilities

This review showed that in Europe relatively little attention has been paid to research on palliative care in long-term care facilities. Much research in the field of palliative care has been focused on patients with specific diseases, such as cancer, and in specific settings, such as inpatient and home palliative care services, which is probably due to the fact that patients residing in long-term care facilities do not often have specific terminal diseases and usually die from complications associated with the final stages of chronic diseases, such as pneumonia.[24] This may contribute to the fact that the care given in long-term care facilities is not always considered as palliative care, to the vagueness on what exactly is the palliative phase in these settings, and that studies in long-term care facilities do not describe the study populations specifically as a palliative care population. However, the studies included in this review, for instance, focused on the last month of life, or terminally ill NH patients and, therefore, have been retrieved by our search terms related to palliative and end-of-life care. The way a study population is defined depends on the aim of the study, and accordingly, in this field of research, whether a long-term care study population is considered as palliative or end-of-life care population or not. Accordingly, it is likely that some studies in which the study population was not specifically described as a palliative care population were not indexed on the literature databases as studies related to palliative care or end-of-life care, and consequently, that they would not have been retrieved by our search strategy. However, in order to develop evidence for these patient groups in the domains of palliative care and to improve research on palliative care in long-term care facilities we need to develop more uniformity in defining the palliative care population.

Furthermore, the system of long-term care in different countries may influence the care given in long-term care facilities. This may also be the reason that there is more research in, for instance, the Netherlands compared to Italy. The long-term care system of Italy and other South European countries is in a pioneering phase, while the Netherlands and Norway have a long tradition of developing a system of long-term care.[33] In addition, in most countries in the South of Europe informal carers provide a significant part of the care given to patients at the end of life,[33] whereas in the Netherlands, a system of public long-term care insurance exists which means that the state bears the responsibility for the elderly in need of long-term care.[34] Moreover, the Netherlands is the only country where NH medicine exists as an independent medical specialism.[35] Since the introduction of NH medicine in 1990, this field has made rapid developments that could probably be ascribed to the fact that this field is getting involved in various scientific research projects developing guidelines and geriatric expertise in this field.[36] This might explain why there is more research on residents approaching the end of their lives in long-term care facilities in the Netherlands than in other European countries.

Study designs

The European studies identified in this review were descriptive: either prospective or retrospective. Accordingly, Froggatt et al.[14] demonstrated that even the literature on interventions and development of tools in the field of palliative care in long-term care facilities was mainly descriptive. However, this study evaluated the current state of science regarding methodology, outcomes and the use of measurement instruments in research on palliative care in long-term care facilities. Descriptive studies are very useful to identify, for instance, relationships between patient characteristics and symptoms, or care needs in long-term care facilities, generating hypotheses for further research.[37] However, high-quality trials and intervention studies will provide more evidence.[38] The randomized controlled trial could be considered as the gold standard of clinical science, because selection bias and confounding are avoided.[39–41] Nevertheless, randomized controlled trials are expensive and not always ethical, and it is difficult to recruit sufficient patients in the last phase of life residing in long-term care facilities to create a sample that is large enough to be successful in removing confounding variables.

However, there are some promising initiatives with regard to gathering patient outcome data and the improvement of palliative care in long-term care facilities: the Liverpool Care Pathway for NHs to improve advance care planning;[42] the Gold Standards Framework for care homes to improve palliative care in the long-term care settings;[43] and initiatives to identify NH managers' understanding of end-of-life care.[44]

Outcome measures and measurement instruments

Mainly the physical domain was measured in the studies included in this review. Symptoms, especially pain, were the most frequently measured outcome in European studies on palliative care in long-term care facilities. This is possibly due to the fact that the emphasis has been laid on the physical aspects of care and, accordingly, most instruments available for this field of research focus on physical symptoms. However, Ferrell et al.[45] and Ferrell[46] emphasize the importance of a range of aspects influencing the quality of care and satisfaction with care given at the end of life.

The studies included in this review used different measurement instruments; only the ESAS and the EORTC QLQ-C30 were used in two different studies, once to measure quality of life and once to measure symptoms. Although several instruments can be used to assess symptoms, the instruments contained a different number of response options, as well as different response scales. Moreover, there is a lack of knowledge on which instruments are valid and most appropriate for use in long-term care settings. Most measurement instruments are not developed and validated in a palliative care population residing in a long-term care facility. Furthermore, many residents are cognitively impaired, which makes using most instruments very complicated. Consequently, many self-report instruments are not useful. Family members or health care professionals are frequently used as proxies; however, studies investigating the agreement between patient and proxy ratings report inconsistent findings.[47–51] Nevertheless, given the high prevalence of dementia in long-term care facilities, proxy assessments are of great significance in studies on palliative care in long-term care facilities.

Limitations

This study has several limitations. Firstly, although, many studies were identified by our search strategy, we cannot be sure that we did not miss any.

Another limitation could be the restriction to papers published after the year 2000, because we wanted to investigate the current state of science. In addition, we only include English language papers, and we focused only on studies conducted in Europe and, consequently, we did not include studies conducted in, for example, the USA or Australia. Consequently, it could be possible that we missed studies published in languages other than English. Furthermore, because we focused on patient outcome data, we did not include, for example, studies on bereavement needs of family members, which should have been included according to the definition of palliative care.

Conclusions and recommendations

In summary, there are only a few European studies on palliative care in long-term care facilities that reported on patient outcome data published in the last 10 years. Long-term care facilities are increasingly responsible for palliative care because more people are now living longer, and more older people, experiencing multiple chronic diseases, need to be cared for in long-term care facilities. Consequently, the care for elderly people in long-term care facilities should be considered as palliative care. Dementia, which affects many long-term care residents, can be considered as a terminal disease and a palliative approach can positively contribute to the quality of care for these patients. Palliative care is not just focused on physical symptoms but focuses also on psychological and spiritual aspects, which makes it an appropriate approach for long-term care residents with their multidimensional care needs.

However, Pautex et al.[52] described that palliative care in long-term care facilities differs from mainstream palliative care with regard to the need for a comprehensive geriatric assessment, the recognition of unique features of symptoms and the comorbidity in these patients.

Furthermore, outcome measurement is of utmost importance for the development and improvement of adequate palliative care in long-term care facilities. Accordingly, measurement instruments validated in a long-term care population who received palliative care are urgently needed. Currently, a project aiming to systematically review the feasibility and clinimetric quality of outcome measures used to assess the quality of palliative care in residential aged care facilities is in progress. To what extent these measurement instruments reflect the concerns of patients requiring palliative care residing in long-term care facilities should be investigated. However, this study will be very helpful for choosing an adequate instrument and to indicate whether future research should focus on the development of new instruments or on further testing of existing (proxy) instruments. In addition, agreement on what can be considered as palliative care in long-term care settings based on a collaborative effort between palliative care researchers and geriatric and NH medicine researchers, and the use of one or a few well-developed instruments might help to make research more comparable and, consequently, provide more evidence. Moreover, to develop adequate palliative care in long-term care facilities multidimensional research, high-quality trails and intervention studies are needed to verify hypotheses defined by the descriptive studies conducted in this field.

References

1. Carone G and Costello D. Can Europe afford to grow old? Int Monetary Fund Finance Dev Mag 2006; 43:28–31.
2. Anderson GF and Hussey PS. Health and population aging: A multinational comparison. New york: The Commonwealth Fund; October 1999.
3. Gomes B and Higginson IJ. Where people die (1974–2030): past trends, future projections and implications for care. Palliat Med 2008; 22: 33–41.
4. Davies E and Higginson IJ (eds) Better palliative care for older people. Geneva: World Health Organization, 2004.
5. World Health Organization. 'Ageing and Life Course, http://www.who.int/ageing/en/ (17 March 2011)
6. West D. A guide to palliative care service development: a population based approach. Palliat Care Aust 2005; 1–48.
7. Bilsen J, Vander SR, Broeckaert B, Mortier F and Deliens L. Changes in medical end-of-life practices during the legalization process of euthanasia in Belgium. Soc Sci Med 2007; 65: 803–808.
8. Cohen J, Bilsen J, Addington-Hall J, Lofmark R, Miccinesi G, Kaasa S, et al. Population-based study of dying in hospital in six European countries. Palliat Med 2008; 22: 702–710.
9. World Health Organization. 'WHO Definition of Palliative Care', http://www.who.int/cancer/palliative/definition/en/ (20 December 2010)
10. Matthews FE and Dening T. Prevalence of dementia in institutional care. Lancet 2002; 360: 225–226.
11. Brandt HE, Ooms ME, Deliens L, van der WG and Ribbe MW. The last two days of life of nursing home patients–a nationwide study on causes of death and burdensome symptoms in The Netherlands. Palliat Med 2006; 20: 533–540.
12. Cartwright JC. Nursing homes and assisted living facilities as places for dying. Annu Rev Nurs Res 2002; 20:231–264.
13. Oliver DP, Porock D and Zweig S. End-of-life care in U.S. nursing homes: a review of the evidence. J Am Med Dir Assoc 2004; 5: 147–155.
14. Froggatt KA, Wilson D, Justice C, MacAdam M, Leibovici K, Kinch J, et al. End-of-life care in long-term care settings for older people: a literature review. Int J Older People Nurs 2006; 1: 45–50.
15. Higginson IJ, Hart S, Koffman J, Selman L and Harding R. Needs assessments in palliative care: an appraisal of definitions and approaches used. J Pain Symptom Manage 2007; 33: 500–505.
16. Harding R and Higginson IJ. PRISMA: a pan-Europeanco-ordinating action to advance the science in end-of-life cancer care. Eur J Canc 2010; 46: 1493–1501.
17. Ribbe MW, Ljunggren G, Steel K, Topinkova E, Hawes C, Ikegami N, et al. Nursing homes in 10 nations: a comparison between countries and settings. Age Ageing 1997; 26(Suppl 2): 3–12.
18. Saysell E and Routley C. Pilot project of an intermediate palliative care unit within a registered care home. Int J Palliat Nurs 2004; 10: 393–398.
19. Van Iersel T, Timmerman D and Mullie A. Introduction of a pain scale for palliative care patients with cognitive impairment. Int J Palliat Nurs 2006; 12: 54–59.
20. Achterberg WP, Pot AM, Scherder EJ and Ribbe MW. Pain in the nursing home: Assessment and treatment on different types of care wards. J Pain Symptom Manage 2007; 34: 480–487.
21. Onwuteaka-Philipsen BD, Pasman HR, Kruit A, van der Heide A, Ribbe MW and van der Wal G. Withholding or withdrawing artificial administration of food and fluids in nursing-home patients. Age Ageing 2001; 30:459–465.
22. Scocco P, Fantoni G, Rapattoni M, de Girolamo G and Pavan L. Death ideas, suicidal thoughts, and plans among nursing home residents. J Geriatr Psychiatr Neurol 2009; 22: 141–148.
23. Veerbeek L, van Zuylen L, Swart SJ, van der Maas PJ and van der HA. The last 3 days of life in three different care settings in The Netherlands. Support Care Canc 2007; 15: 1117–1123.
24. Brandt HE, Deliens L, van der Steen JT, Ooms ME, Ribbe MW and van der WG. The last days of life of nursing home patients with and without dementia assessed with the palliative care outcome scale. Palliat Med 2005; 19: 334–342.
25. van der Steen JT, Gijsberts MJ, Knol DL, Deliens L and Muller MT. Ratings of symptoms and comfort in dementia patients at the end of life: comparison of nurses and families. Palliat Med 2009; 23: 317–324.
26. Jordhoy MS, Saltvedt I, Fayers P, Loge JH, Ahlner-Elmqvist M and Kaasa S. Which cancer patients die in nursing homes? Quality of life, medical and sociodemographic characteristics. Palliat Med 2003; 17: 433–444.
27. Pautex S, Berger A, Chatelain C, Herrmann F and Zulian GB. Symptom assessment in elderly cancer patients receiving palliative care. Crit Rev Oncol Hematol 2003; 47: 281–286.
28. Di Giulio P, Toscani F, Villani D, Brunelli C, Gentile S and Spadin P. Dying with advanced dementia in long-term care geriatric institutions: a retrospective study. J Palliat Med 2008; 11: 1023–1028.
29. Pautex S, Herrmann FR, Le Lous P, Ghedira M, Zulian GB, Michon A, et al. Symptom relief in the last week of life: Is dementia always a limiting factor? J Am Geriatr Soc 2007; 55: 1316–1317.
30. van der Steen JT, Pasman HR, Ribbe MW, van der Wal G and Onwuteaka-Philipsen BD. Discomfort in dementia patients dying from pneumonia and its relief by antibiotics. Scand J Infect Dis 2009; 41: 143–151.
31. van der Steen JT, Ooms ME, Mehr DR, van der Wal G and Ribbe MW. Severe dementia and adverse outcomes of nursing home-acquired pneumonia: evidence for mediation by functional and pathophysiological decline. J Am Geriatr Soc 2002; 50: 439–448.
32. van der Steen JT, Kruse RL, Ooms ME, Ribbe MW, van der Wal G, Heintz LL, et al. Treatment of nursing home residents with dementia and lower respiratory tract infection in the United States and the Netherlands: an ocean apart. J Am Geriatr Soc 2004; 52: 691–699.
33. EAARP. European leadership study: European experiences with long-term care France, the Netherlands, Norway, and the United Kingdom. EAARP, 2006.

34. Ministry of Welfare, Health and Cultural Affairs. Health care in the Netherlands, Fact Sheet V-7-E. The Hague: The Netherlands, 2003.
35. Ribbe MW. Care for the elderly: the role of the nursing home in the Dutch health care system. Int Psychogeriatr 1993; 5: 213–222.
36. Hoek JF, Ribbe MW, Hertogh CM and van der Vleuten CP. The role of the specialist physician in nursing homes: the Netherlands' experience. Int J Geriatr Psychiatr 2003; 18: 244–249.
37. Grimes DA and Schulz KF. Descriptive studies: what they can and cannot do. Lancet 2002; 359: 145–149.
38. Evans D. Hierarchy of evidence: a framework for ranking evidence evaluating healthcare interventions. J Clin Nurs 2003; 12: 77–84.
39. Muir Gray JA. Evidence-based healthcare. New York:Churchill Livingstone, 1997.
40. Mulrow CD and Oxman AD. Cochrane collaboration handbook. Oxford: The Cochrane Library, The Cochrane Collaboration, 1997.
41. Sackett DL, Richardson WS, Rosenberg W and Haynes RB. Evidence Based medicine: how to practice and teach EBM. New York: Churchill Livingstone, 1997.
42. Mathews K and Finch J. Using the Liverpool Care Pathway in a nursing home. Nurs Times 2006; 102: 34–35.
43. Hewison A, Badger F, Clifford C and Thomas K. Delivering 'Gold Standards' in end-of-life care in care homes: a question of teamwork? J Clin Nurs 2009; 18:1756–1765.
44. Froggatt K and Payne S. A survey of end-of-life care in care homes: issues of definition and practice. Health Soc Care Community 2006; 14: 341–348.
45. Ferrell B, Connor SR, Cordes A, Dahlin CM, Fine PG, Hutton N, et al. The national agenda for quality palliative care: the National Consensus Project and the National Quality Forum. J Pain Symptom Manage 2007; 33: 737–744.
46. Ferrell BR. Overview of the domains of variables relevant to end-of-life care. J Palliat Med 2005; 8 Suppl 1: S22–S29.
47. Higginson I, Priest P and McCarthy M. Are bereaved family members a valid proxy for a patient's assessment of dying? Soc Sci Med 1994; 38: 553–557.
48. Kristjanson LJ, Nikoletti S, Porock D, Smith M, Lobchuk M and Pedler P. Congruence between patients' and family caregivers' perceptions of symptom distress in patients with terminal cancer. J Palliat Care 1998; 14: 24–32.
49. Nekolaichuk CL, Bruera E, Spachynski K, MacEachern T, Hanson J and Maguire TO. A comparison of patient and proxy symptom assessments in advanced cancer patients. Palliat Med 1999; 13: 311–323.
50. Nekolaichuk CL, Maguire TO, Suarez-Almazor M, Rogers WT and Bruera E. Assessing the reliability of patient, nurse, and family caregiver symptom ratings in hospitalized advanced cancer patients. J Clin Oncol 1999; 17: 3621–3630.
51. Zloklikovits S, Andritsch E, Frohlich B, Verebes J, Dietmaier G and Samonigg H. Assessing symptoms of terminally-ill patients by different raters: a prospective study. Palliat Support Care 2005; 3: 87–98.
52. Pautex S, Curiale V, Pfisterer M, Rexach L, RibbeMand Van Den NN. A common definition of geriatric palliative medicine. J Am Geriatr Soc 2010; 58: 790–791.

Appendix 1

Search term included in the search strategy

palliative care
palliative nursing
palliative therapy
palliation
palliative medicine
palliative radiotherapy
palliative surgery
palliative treatment
terminal care
terminally ill patients
end-of-life care
end of life
dying
death
nursing home
nursing home patient
nursing home resident
long term care patient
nursing home
intermediate care facilities
skilled nursing facilities
residential home
residential institution
residential care institution
residential facility
assisted living facilities
homes for the aged
homes for the aged
housing for the elderly
old age home
old people home
elderly care
aged
frail elderly
geriatric nursing
geriatric patients
geriatrics
gerontology

Part II

Measuring quality of life in palliative care

Chapter 3

Content and spiritual items of quality-of-life instruments appropriate for use in palliative care: a review

Gwenda Albers, Michael A Echteld, Henrica CW de Vet, Bregje D Onwuteaka-Philipsen, Mecheline HM van der Linden, Luc Deliens

Published in Journal of Pain and Symptom Management 2010, 40(2):290

Abstract

Background
Despite the importance of palliative care and quality of life (QoL) as an outcome measure, little research evaluated the QoL instruments that are used in end-of-life situations.

Aim
The aim of this study was to evaluate the content of and domains measured by QoL instruments that are suitable for use in palliative care and how the domain of spirituality was operationalized in these instruments.

Methods
We conducted two literature reviews. One identified the domains that are most important for the QoL of incurably ill patients and resulted in a framework of QoL domains. The other review identified 29 instruments measuring (at least one domain of) QoL that are appropriate for use in palliative care.

Results
Most of the instruments covered only one or two QoL domains, and none of the instruments covered all QoL domains included in the framework. Among the 29 instruments, 15 included items on spirituality. We also categorized the spirituality items contained in the instruments into the spirituality aspects in the framework. Most spirituality items concerned the meaning or purpose of life.

Conclusion
This study provides information about the domains included in QoL instruments that are suitable for use in palliative care and provides insights into the differences in content, which can be helpful when choosing an instrument for use in palliative care.

Introduction

Interest in palliative care has increased in recent decades. Palliative care is defined by the World Health Organization as active total care, of which the main interests are: control of pain; other symptoms; and psychological, social and spiritual problems.[1] The main purpose of palliative care is to improve the quality of life (QoL) of patients for whom there are no curative treatment options, and their families. Therefore, QoL has become an important outcome measure in palliative care research, and as a consequence, there are various QoL instruments that can be applied in palliative care.

In the literature, QoL is considered as a multidimensional construct. Physical, psychological, social and spiritual aspects have been identified as domains that are of great importance to a patient's total well-being.[2, 3] However, there is no consensus on the number of relevant domains or on the content of the QoL domains. Consequently, there is considerable difference in the content and domains of the various QoL instruments.

Despite the growing importance of palliative care and quality of life as an outcome measure, little research has evaluated the content of the QoL instruments that are used in end-of-life care research. Only one study has compared the content of QoL instruments, but this comparison was based on the International Classification of Functioning, Disability and Health, which mainly focuses on physical domains.[4] Many studies have identified the feasibility and clinimetric quality of QoL questionnaires,[5-10] including our previous review,11 which may be of help when choosing an instrument for palliative care research or clinical practice. However, to make a well-informed decision about the appropriate instrument for palliative care research, additional information about the domains that are included in the instrument is of major importance. Additionally, an overview of the content of such instruments is also significant for further development of the instruments; it will indicate the domains of QoL that are insufficiently covered by the existing instruments.

Although palliative care focuses on a patient's total well-being, much emphasis has been laid on the physical domain in the assessment of QoL in palliative care,[12] and many instruments that are used in palliative care also contain items related to psychosocial problems. We hypothesized that items concerning spirituality are seldom included in the majority of QoL instruments, although spiritual issues become more and more important at the end of life. Steinhauser et al.[13, 14] studied seriously ill patients and found that existential issues had become more important to these patients since they became ill.

Furthermore, research indicates that the existential or spiritual domain is an important determinant of QoL in the palliative care setting,[15] probably because spirituality or existential issues may offer a way in which to cope with the illness and the illness-related difficulties. Moreover, it has been recommended in the literature that studies with QoL as an outcome measure should take the spiritual and religious concerns of patients into account because such concerns play a role in QoL.[15, 16] However, there is no consensus about the definition of spirituality or how to measure it. Spirituality relates to the search for a meaning and purpose of life, the connection with a transcendent dimension of existence, and the experiences and feelings associated with that search.[15, 17]

The main objective of this study is to provide an overview, and to compare the content of and domains measured by the existing QoL instruments that are suitable for use in palliative care. The second objective was to examine the domain of spirituality at item-level, and to evaluate how this domain is operationalized in the existing quality-of-life instruments. This information should facilitate the process of selecting a QoL instrument for use in palliative care.

Methods

Search strategies

This study included two literature reviews: the aim of one review was to identify the domains that are most important for the QoL of incurably ill patients, and the aim of the other was to identify instruments that can be used to measure these QoL domains.

For the first review, we performed a non-systematic literature research to identify theoretical and overview papers focusing on the QoL domains that are most important for patients for whom there are no curative treatment options. We searched PubMed for empirical studies and review articles about QoL questionnaires that are appropriate for use in palliative care. These studies described the item selection procedure, which in general included the involvement of patients and QoL experts. The search terms we used were: 'quality of life', 'palliative', 'end-of-life', 'questionnaire', 'assessment', 'psychometric'. We also searched for studies which used the Schedule for Evaluation of Individual Quality of Life (SEIQoL),[18, 19] a semi-structured interview protocol in which patients are asked to nominate domains of life that influence the quality of their life. We examined the patient-generated domains that were listed in the studies in which the SEIQoL was used in a population of incurably ill patients.

Secondly, we performed a systematic literature review to identify QoL instruments that are appropriate for use in palliative care. We searched PubMed, Embase, CINAHL and PsychINFO from 1990 up to April 2008, using a methodological search filter to identify instruments' measurement properties and terms related to palliative care and quality of life.[20] Because spirituality is somewhat underrepresented in QoL instruments, we added the search term "spiritual" in our search strategy, and this yielded 2015 hits. We screened the titles and abstracts of all these references, with the following inclusion criteria: 1) the study should describe the development or validation of a measurement instrument, 2) the instrument should measure at least one domain of QoL in a population of patients with no further curative treatment options, 3) the study should evaluate at least one measurement property of the instrument, and 4) the instrument was validated in an English or Dutch population. Ninety-six studies met the inclusion criteria. We finally identified 29 instruments that measure at least one domain of QoL. That systematic review, in which we focused on measurement properties, is described in more detail elsewhere.11 In the present review we focus on the content of these 29 instruments (see Appendix for full names of instruments).

Data-extraction

Relevant studies retrieved from the review of the QoL domains included, for instance, conceptual frameworks, indicators that are relevant for the evaluation of QoL, or aspects that are important for the QoL of palliative care patients. We extracted from these studies information about all domains and associated aspects. We subsequently made a framework that included the domains of QoL that are most important for incurable patients, and then classified the underlying aspects that are relevant to these domains. Discussions among the authors resulted in consensus about the domains and the aspects that are relevant to these domains.

We identified the domains that were designed to be measured by the instruments identified in the review of the QoL measures. To determine which QoL domains are covered by the instruments, we assigned the domains included in the QoL instruments within the framework identified in the first review. We used the domains as mentioned by the researchers who developed the instrument and did not consider the items included in the instruments. In this way, we made an overview of the content of and domains measured by the different QoL instruments that are appropriate for palliative care.

In addition, we categorised the spirituality items included in the QoL instruments into the aspects of spirituality identified in the first literature review focusing on the QoL domains organised in the QoL framework. Because we could not categorise two items into any of the aspects of spirituality, we added one aspect to the framework to accommodate these two items: "evaluation of life". The categorization of the spirituality items was based on consensus that we achieved by discussion among the authors and after consultation with several experts.

The spirituality items of three instruments (McGill Quality of Life Questionnaire-Cardiff Short Form [MQOL-CSF], Missoula-VITAS Quality of Life Index [MQLI]-Revised and Problems and Needs in Palliative Care questionnaire [PNPC]-short version) were not categorised because these instruments were revised versions that included the same spirituality items as the original instruments (MQOL, MVQOLI and PNPC) that were already included. The spirituality items of the McCanse Readiness for Death Instrument (MRDI) were not included because we could not find a full description of the instrument, and therefore information about the items was missing.

Results

Table 1 presents the QoL framework, which is based on the first literature search to identify QoL domains. The framework shows the domains that are most important for incurably ill patients. Each domain includes several aspects associated with the domain. The domain of psychological well-being included the greatest variety of aspects.

Table 1 QoL Framework Appropriate for Palliative Care

Domains of quality of life	Aspects included in the domain
Physical comfort	Pain and other symptoms (shortness of breath, weakness, fatigue, nausea/vomiting, appetite, dry mouth, coughing, sleep problems, constipation, diarrhoea, incontinence) that cause physical discomfort. Ability to control/manage symptoms without undesired side effects.
Physical functioning	Activities of daily living (ADL), mobility, activity, ability to care for self, work/profession, hobby, leisure activities
Cognitive functioning	Comprehension, attention, awareness, concentration, memory
Psychological well-being	Emotions (anxiety, fear, panic, depression, sadness, loneliness, mourning, worries about family burdened with patient's health care expenses [finances]) Dignity* (self-worth, sense of being valued as a person, not being a burden to others, privacy, body image, sense of being attractive/clean) Control/autonomy (perceived control over daily living, choices, preferences, feeling in control of the overall dying process, ability to die on one's own terms)
Social well being	Communication, support, sense of closure or connectedness with family, children, friends, colleagues
Spiritual well-being	Purpose of life, meaning(fullness) of life, acceptance of death, feeling at peace with life, feeling at peace with God, preparation for death, religion, evaluation of life
Perceived quality of care	Services and treatment, information, accommodation, advance care planning, place of death

* Although not possible within this table, dignity can be considered to cover all domains[23]

Table 2 Domains Contained in QoL Instruments for Use in Palliative Care

Instrument	*Domains according to the authors of the instrument*	*Physical comfort*	*Physical functioning*	*Cognitive functioning*	*Psychological well-being*	*Social well-being*	*Spiritual well-being*	*Perceived quality of care*	*Overall QoL*	*Number of domains covered*
BHI	Symptoms; QoL	•							•	2
CAMPAS-R	Symptoms (physical and psychological)	•			•					2
CMSAS	Physical and psychological symptoms	•			•					2
DS	Loss of meaning; Dysphoria; Disheartenment, Helplessness; Sense of failure				•		•			2
EFAT	Symptoms and functions	•	•							2
Emanuel and Emanuel Medical Directive**	*Patient-generated*							•		1
EORTC QLQ-OES18	Dysphagia; Eating restrictions; Pain; Reflux	•								1
EORTC QLQ-STO22	Dysphagia; Eating restrictions; Pain; Reflux; Anxiety	•								1
ESAS	Symptoms	•								1
FACIT-Pal	Symptoms; Family and friend relationships; Life closure issues; Decision making and communication abilities	•				•	•	•		4
HQLI	Psychophysiological; Functioning; Social/spiritual	•	•		•	•	•			5
LCS	Self-reconciled; Self-restructuring				•					1
LEQ	Freedom; Appreciation of life; Contentment, Resentment; Social Integration				•	•				2
MQLS	Physical, Cognition, Social, Energy, Role, Rest, Function, Emotion	•	•	•	•	•				5
MQOL	Psychological symptoms; Existential well-being; Support; Physical symptoms	•			•	•	•			4

Instrument	*Domains according to the authors of the instrument*	*Physical comfort*	*Physical functioning*	*Cognitive functioning*	*Psychological well-being*	*Social well-being*	*Spiritual well-being*	*Perceived quality of care*	*Overall QoL*	*Number of domains covered*
MQOL-CSF	Global QoL; Physical symptoms; Psychological; Existential	•			•		•		•	4
MRDI	Physiological; Psychological; Sociological; Spiritual	•			•	•	•			4
MSAS	Global distress; Physical; Psychological	•			•					2
MSAS-GDI	Psychological symptoms; physical symptoms	•			•					2
MVQOLI	Symptoms; Function; Interpersonal; Well-being; Transcendence	•	•				•			3
NA-ACP	Medical communication/information; Psychological/emotional; Daily living; Financial; Symptom; Spiritual; Social	•	•		•	•	•	•		6
PAQ	Autonomy				•					1
PDI	Symptom distress; Existential distress; Dependency; Peace of mind; Social support	•				•	•			3
PNPC	ADL&IADL; Physical Symptoms; Role activities; Financial; Social; Psychological; Spiritual; Autonomy; Informational Needs; Quality-of-Care aspects	•	•		•	•	•	•		6
PNPC-sv	ADL&IADL; Physical Symptoms; Financial; Social; Psychological; Spiritual; Autonomy; Informational needs	•	•		•	•	•	•		6
POS	Physical; Psychological; Spiritual	•			•		•			3
QODD	Symptoms and personal care; Preparation for death, Moment of death; Family; Treatment preferences; Whole person concerns	•				•		•		3
QUAL-E	Life completion; Relationship with health care provider; Preparation						•	•		2
SNI	Outlook; Inspiration; Spiritual activities; Religion; Community						•			1
Total		25	9	1	18	11	15	7	2	

Table 3 presents the spirituality items per instrument, categorized into the aspects of spirituality from the QoL framework (Table 1). Five of the 11 instruments included in Table 3 contained five or more spirituality items, and eight of the ten instruments included covered at least two aspects of spirituality. All but one instrument included one or more items categorized into "purpose of life" or "meaning of life". Six instruments included spirituality items on "feeling at peace with life", two instruments included "evaluation of life" and three instruments included "feeling at peace with God". Items on "preparation for death" and "acceptance of death" were scarcely included in these instruments. The Spiritual Needs Inventory (SNI) and Needs Assessment for Advanced Cancer Patients (NA-ACP) are the only two instrument that included items on "religion," on religious activities such as "praying," "clarifying spiritual beliefs", and "talking with someone about religious or spiritual issues," whereas the other instruments included items on feelings and outcomes regarding meaning/purpose of life, relationships with self and others, and spiritual and existential issues. The spiritual subscales of two questionnaires included items that we categorized into another domain, and not spirituality. We categorized "I feel hopeful" into the domain of psychological well-being, because hopefulness is associated with emotions, and we categorized the item "How satisfied are you with the spiritual support you get from your health care team?" into the domain of perceived quality of care.

Table 3 Spirituality Items from QoL Instruments appropriate for Use in Palliative Care or End-of-Life Care

Instrument	Wordings of spirituality items						Spirituality aspect measured
DS	***For each statement below, please indicate how strongly you have felt this way over the last two weeks by circling the corresponding number.***						
		Never	*Seldom*	*Sometimes*	*Often*	*All the time*	
	• There is a lot of value in what I can offer others	0	1	2	3	4	Purpose of life
	• My life seems to be pointless	0	1	2	3	4	Purpose of life
	• There is no purpose to the activities in my life	0	1	2	3	4	Purpose of life
	• My role in life has been lost	0	1	2	3	4	Purpose of life
	• I have a lot of regret about my life	0	1	2	3	4	Feeling at peace with life
	• Life is no longer worth living	0	1	2	3	4	Meaning of life
FACIT-Pal	*By circling one number per line, please indicat1e how true each statement has been for you during the past seven days.*						
		Not at all	*A little bit*	*Somewhat*	*Quite a bit*	*Very much*	
	• I feel useful	0	1	2	3	4	Purpose of life
	• I make each day count	0	1	2	3	4	Purpose of life
	• I have peace of mind	0	1	2	3	4	Feeling at peace with life
	• I feel hopeful	0	1	2	3	4	*Psychological well-being**
HQLI	• How meaningful is your life? Not at all meaningful -- 0 1 2 3 4 5 6 7 8 9 10 -- Very meaningful						Meaning of life
	• How satisfied are you with your relationship with God (however you define that relationship)? Very dissatisfied -- 0 1 2 3 4 5 6 7 8 9 10 -- Very satisfied						Feeling at peace with God
	• How satisfied are you with the spiritual support you get from your health care team? Very dissatisfied -- 0 1 2 3 4 5 6 7 8 9 10 -- Very satisfied						*Perceived quality of care**
MQOL	• Over the past two days, my life has been: Utterly meaningless and without purpose -- 0 1 2 3 4 5 6 7 8 9 10 -- Very purposeful and meaningful						Purpose of life
	• Over the past two days, when I thought about my whole life, I felt that in achieving life goals I Made no progress whatsoever -- 0 1 2 3 4 5 6 7 8 9 10 -- Progressed to complete fulfilment						Purpose of life
	• Over the past two days, when I thought about my life, I felt that my life to this point had been: Completely worthless -- 0 1 2 3 4 5 6 7 8 9 10 -- Very worthwhile						Evaluation of life

Instrument	Wordings of spirituality items						Spirituality aspect measured
MVQOL	***Indicate the extent to which you agree or disagree with the following statements by marking in one of the circles below the question.***						
		Strongly agree	*Agree*	*Neutral*	*Disagree*	*Strongly disagree*	
	• I feel more disconnected from all things now than I did before my illness	1	2	3	4	5	Feeling at peace with life
	• I have a better sense of meaning in my life now than I have had in the past	1	2	3	4	5	Purpose of life
	• I am comfortable with the though of my own death	1	2	3	4	5	Acceptance of death
	• Life has lost all value for me; every day is a burden	1	2	3	4	5	Purpose of life
	• It is important to me to feel that my life has meaning	1	2	3	4	5	Meaning of life
NA-ACP	***In the last four months, what was your level of need for help with:***	***No need/not appli****cable - No need/satisfied - Low need - Moderate need - High need*					
	• Clarifying your spiritual beliefs	1	2	3	4	5	Religion
	• Setting new priorities for your life	1	2	3	4	5	Meaning of life
	• Dealing with unmet life goals	1	2	3	4	5	Feeling at peace with life
	• Accepting your relationship with God or a higher being	1	2	3	4	5	Feeling at peace with god
	• Being able to see your priest, chaplain or minister	1	2	3	4	5	Religion
	• Dealing with spiritual issues of death and dying	1	2	3	4	5	Acceptance of death
	• Trying to find meaning in your cancer experience	1	2	3	4	5	Meaning of life
	• Being able to choose the place where you want to die	1	2	3	4	5	Preparation for death
	• Assistance having your spiritual needs met	1	2	3	4	5	Religion
PDI	***For each item, please indicate how much of a problem or concern these have been for you within the last few days***						
		Not a problem - A slight problem - A problem - A major problem - An overwhelming problem					
	• Not feeling worthwhile or valued	1	2	3	4	5	Purpose of life
	• Feeling that life no longer has meaning or purpose	1	2	3	4	5	Purpose of life
	• Feeling that I have not made a meaningful and lasting contributing during my lifetime	1	2	3	4	5	Evaluation of life
	• Feeling that I have 'unfinished business' (e.g. things unsaid, or incomplete)	1	2	3	4	5	Feeling at peace with life
	• Concern that my spiritual life is not meaningful	1	2	3	4	5	Meaning of life

Instrument	Wordings of spirituality items						Spirituality aspect measured
PNPC	*Is this (item) a problem?*						
	• Difficulties to be engaged usefully	Yes – Somewhat – No					Purpose of life
	• Finding it hard to be available to others	Yes – Somewhat – No					Purpose of life
	• Difficulties in keeping confidence in God or religion	Yes – Somewhat – No					Feeling at peace with God
	• Difficulties concerning the meaning of death	Yes – Somewhat – No					Acceptance of death
	• Difficulties in accepting the disease	Yes – Somewhat – No					Acceptance of death
POS	Over the past 3 days, did you felt life was worth living?	☐0	Yes, all the time				Purpose of life
		☐1	Most of the time				
		☐2	Sometimes				
		☐3	Occasionally				
		☐4	No, not at all				
QUAL-E	***Below is a list of statements that other people with a serious illness have said may be important. Please tell me how true each statement is for you.***						
		Not at all - A little bit - A moderate amount - Quite a bit - Completely					
	• I have regrets about the way I have lived my life	1	2	3	4	5	Feeling at peace with life
	• Despite my illness, I have a sense of meaning in my life	1	2	3	4	5	Meaning of life
	• I feel at peace	1	2	3	4	5	Feeling at peace with life
SNI		*In order to live your life fully, do you need to …?*		*Do you think this is a spiritual need?*		*Is this need currently met in your life?*	
	• Read a religious text	1 – 2 – 3 – 4 - 5		Yes - No		Yes - No	Religion
	• Talk with someone about religious or spiritual issues	1 – 2 – 3 – 4 - 5		Yes - No		Yes - No	Religion
	• Be with people who share my spiritual beliefs	1 – 2 – 3 – 4 - 5		Yes - No		Yes - No	Religion
	• Use inspirational material	1 – 2 – 3 – 4 - 5		Yes - No		Yes - No	Religion
	• Use phrases from a religious text	1 – 2 – 3 – 4 - 5		Yes - No		Yes - No	Religion
	• Read inspirational materials	1 – 2 – 3 – 4 - 5		Yes - No		Yes - No	Religion
	• Pray	1 – 2 – 3 – 4 - 5		Yes - No		Yes - No	Religion
	• Go to religious services	1 – 2 – 3 – 4 - 5		Yes - No		Yes - No	Religion

* We categorized the items into another domain than spirituality.

Discussion

This study presented a QoL framework including the domains and associated aspects that are most important for incurably ill patients. One domain in the framework, psychological well-being, contained the greatest variety of aspects. The results of this study also showed that the content of and the domains covered by QoL instruments that are appropriate for use in palliative care vary greatly. Most of the instruments covered only one or two QoL domains, and none of the instruments covered all QoL domains within the framework. Furthermore, some domains that are relevant to QoL were seldom included in the instruments. The results did not support our hypothesis that the domain of spirituality is seldom covered by QoL instruments. Among the 29 instruments that we identified as suitable for use in palliative care, 15 included spirituality items, and most of them contained items regarding “purpose or meaning of life” and “feeling at peace with life”.

The quality-of-life framework

It is important to realize that some aspects included in the framework may also be relevant to more than one domain. For example, “hobby” and “leisure” could be categorized into the domain of social well-being, as well as the domain of physical functioning; “control/autonomy” and “loneliness” could be categorized into the domain of social well-being, as well as psychological well-being; and “acceptance of death” and “feeling at peace with life or God” could be categorized into the domain of psychological well-being, as well as the domain of spiritual well-being. In the framework, we categorized “dignity” into the domain of psychological well-being, but dignity is comparable in breadth and level of abstraction to the concept of QoL. Dignity can be considered as an outcome that could be affected by almost all other QoL domains and, therefore, as an aspect of all QoL domains. Additionally, it is important to emphasize that the overview (and comparison) of the content of the QoL instruments is based on the domains as assigned by the researchers who developed the instruments.

The quality-of-life domains

The 29 instruments contained a varying number of domains. Only one instrument contained a subscale for cognitive functioning. A possible explanation for this may be that almost all instruments were self-report questionnaires, designed to be completed by the patient and, therefore, not applicable for cognitively impaired patients. Another remarkable result is that we underestimated the number of QoL instruments measuring spiritual issues. This is possibly because of the lack of a clear definition of spirituality. Furthermore, because our aim was to investigate the spiritual sub scale more extensively, we added “spiritual” to the search strategy to identify QoL instruments that contained spiritual items, and we found four extra instruments containing items on spirituality because of this extra search term.

The domain of spirituality

Spirituality is not well-defined, but there is consensus that spirituality is a concept that is broader and more inclusive than religion.[22, 23] This is reflected in our results: most of the spirituality items concerned the meaning and purpose of life and death. However, is it notable that only two instruments contained items on religion, altough it is obvious that religion is a dimension of spirituality. Nowadays, spirituality is seen as a fundamental issue in palliative care.[23] So to improve our knowledge about spiritual issues at the end of life, to provide spiritual care, and to recognize a patient's spiritual needs, a clear definition of the concept of spirituality is imperative. In addition, a clear definition will provide information on the extent to which instruments fully cover the spirituality domain.

Limitations and recommendations
None of the instruments in this study contained all the domains of QoL that were included in the framework. The PNPC questionnaire and the NA-ACP both cover the most domains of QoL compared with the other instruments. In addition, the latter instrument covers the most aspects of spirituality. However, when selecting an instrument to measure QoL for use in palliative care research or clinical practice, one must first decide what should be measured, taking into consideration the aim of the study or the care needs. Consequently, the aim of the research, the study population, and the type of intervention or the care needs may dictate a specific content of the instrument. Furthermore, when choosing an instrument, aspects such as feasibility and clinimetric quality also must be taken into account. Therefore, given the many parameters involved in choosing an instrument, and the lack of guidance from the literature, we cannot select one or a few instruments which are the most appropriate for measuring QoL in palliative care. Hence, an international expert group meeting on QoL instruments for use in palliative care could be valuable to move forward to provide more help in selecting the most appropriate instruments for use in palliative care research. Such an expert group also could provide consensus-based guidelines that are necessary for the development, validation and translation of QoL instruments for palliative care.

However, it should be stated that the comparison of the content of QoL instruments presented in this article provides information about the domains included in the various instruments that are suitable for use in palliative care or end-of-life care, and provides insight in the differences in the content of these instruments. Moreover, we have elaborated on the categorization of spirituality items, which provides insight into how and the extent to which spirituality is measured by these instruments. In addition to our previous article, which provides information on the feasibility characteristics and the clinimetric quality of the instruments,[11] the information in this article can help to make a well-informed decision on the use of a QoL instrument for use in palliative care.

References

1. http://www.who.int/cancer/palliative/definition/en/. Accessed October 8, 2010.
2. Ferrans CE. Development of a conceptual model of quality of life. Sch Inq Nurs Pract 1996;10(3):293- 304.
3. Ferrell B, Grant M, Padilla G, Vemuri S, Rhiner M. The experience of pain and perceptions of quality of life: validation of a conceptual model. Hosp J 1991;7(3):9-24.
4. Cieza A, Stucki G. Content comparison of health-related quality of life (HRQOL) instruments based on the international classification of functioning, disability and health (ICF). Qual Life Res 2005 Jun;14(5):1225-37.
5. Bruley DK. Beyond reliability and validity: analysis of selected quality-of-life instruments for use in palliative care. J Palliat Med 1999;2(3):299-309.
6. Hearn J, Higginson IJ. Outcome measures in palliative care for advanced cancer patients: a review. J Public Health Med 1997 Jun;19(2):193-9.
7. Kaasa S, Loge JH. Quality-of-life assessment in palliative care. Lancet Oncol 2002 Mar;3(3):175-82.
8. Massaro T, McMillan SC. Instruments for assessing quality of life in palliative care settings. Int J Palliat Nurs 2000 Oct;6(9):429-33.
9. McMillan SC. Quality-of-Life Assessment in Palliative Care. Cancer Control 1996 May;3(3):223-9.
10. Mularski RA, Dy SM, Shugarman LR, Wilkinson AM, Lynn J, Shekelle PG, et al. A systematic review of measures of end-of-life care and its outcomes. Health Serv Res 2007 Oct;42(5):1848-70.
11. Albers G, Echteld MA, de Vet HCW, Onwuteaka-Philipsen BD, van der Linden MHM, Deliens L. Evaluation of quality-of-life measures for use in palliative care: a systematic review. Palliat Med 2010, 24(1):17.
12. Jordhoy MS, Inger RG, Helbostad JL, Oldervoll L, Loge JH, Kaasa S. Assessing physical functioning: a systematic review of quality of life measures developed for use in palliative care. Palliat Med 2007 Dec;21(8):673-82.
13. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 2000 Nov 15;284(19):2476-82.
14. Steinhauser KE, Voils CI, Clipp EC, Bosworth HB, Christakis NA, Tulsky JA. "Are you at peace?": one item to probe spiritual concerns at the end of life. Arch Intern Med 2006 Jan 9;166(1):101-5.
15. Cohen SR, Mount BM, Tomas JJ, Mount LF. Existential well-being is an important determinant of quality of life. Evidence from the McGill Quality of Life Questionnaire. Cancer 1996 Feb 1;77(3):576-86.
16. Vivat B. Measures of spiritual issues for palliative care patients: a literature review. Palliat Med 2008 Oct;22(7):859-68.
17. Peterman AH, Fitchett G, Brady MJ, Hernandez L, Cella D. Measuring spiritual well-being in people with cancer: the functional assessment of chronic illness therapy--Spiritual Well-being Scale (FACIT-Sp). Ann Behav Med 2002;24(1):49-58.

18. Joyce CR, Hickey A, McGee HM, O'Boyle CA. A theory-based method for the evaluation of individual quality of life: the SEIQoL. Qual Life Res 2003 May;12(3):275-80.
19. O'Boyle CA, Browne JP, Hickey A, McGee HM, Joyce CRB. Schedule for the Evaluation of Individual Quality of Life (SEIQoL): a direct weighting procedure for quality of life. Administration Manual. Dublin: Royal College of Surgeons; 1995.
20. Terwee CB, Jansma EP, Riphagen I, de Vet HCW. Development of a methodological PubMed search filter for finding studies on measurement properties of measurement instruments. Qual Life Res 2009 Oct;18(8):1115-23.
21. Astrow AB, Puchalski CM, Sulmasy DP. Religion, spirituality, and health care: social, ethical, and practical considerations. Am J Med 2001 Mar;110(4):283-7.
22. Rumbold BD. Caring for the spirit: lessons from working with the dying. Med J Aust 2003 Sep 15;179(6 Suppl):S11-S13.
23. Okon TR. Spiritual, religious, and existential aspects of palliative care. J Palliat Med 2005 Apr;8(2):392-414.

Appendix

Abbreviations and Full Names of the Instruments

BHI	Brief Hospice Inventory
CAMPAS-R	Cambridge Palliative Audit Schedule
DS	Demoralization Scale
EFAT	Edmonton Functional Assessment Tool
EFAT-2	Edmonton Functional Assessment Tool (revised version)
EORTC QLQ-OES18	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Oesophageal cancer module
EORTC QLQ-STO22	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Gastric cancer module
ESAS	Edmonton Symptom Assessment Scale
FACIT-Pal	Functional Assessment of Chronic Illness Therapy-Palliative subscale
HQLI	Hospice Quality of Life Index
LCS	Life Closure Scale
LEQ	Life Evaluation Questionnaire
MQLS	McMaster Quality of Life Scale
MQOL	McGill Quality of Life Questionnaire
MQOL-CSF	McGill Quality of Life Questionnaire-Cardiff Short Form
MRDI	McCanse Readiness for Death Instrument
MSAS	Memorial Symptom Assessment Scale
MSAS (FC)	Memorial Symptom Assessment Scale (Family Caregivers)
CMSAS	Condensed Memorial Symptom Assessment Scale
MSAS-GDI	Memorial Symptom Assessment Scale-Global Distress Index
MVQOLI	Missoula-VITAS Quality of Life Index
MVQOLI-R	Missoula-VITAS Quality of Life Index - Revised
NA-ACP	Needs Assessment for Advanced Cancer Patients
PAQ	Patient Autonomy Questionnaire
PDI	Patient Dignity Inventory
PNPC	Problems and Needs in Palliative Care questionnaire
PNPC-sv	Problems and Needs in Palliative Care questionnaire-short version
POS	Palliative care Outcome Scale
QODD	Quality of Dying and Death questionnaire
QUAL-E	Quality of life at the end of life
SNI	Spiritual Needs Inventory

Chapter 4

Evaluation of quality-of-life measures for use in palliative care: A systematic review

Gwenda Albers, Michael A Echteld, Henrica CW de Vet, Bregje D Onwuteaka-Philipsen, Mecheline HM van der Linden, Luc Deliens

Published in Palliative Medicine 2010, 24(1):17

Abstract

Purpose
In this literature review we evaluated the feasibility and clinimetric quality of quality-of-life (QoL) measurement instruments suitable for use in palliative care.

Methods
We conducted a systematic literature review to identify instruments measuring (at least one domain of) QoL. We selected articles that present data on patients receiving palliative care and at least one measurement property. A checklist was used to describe the characteristics of the instruments, and a widely accepted rating list was used to evaluate the clinimetric aspects.

Results
29 instruments were identified and evaluated, most of which were targeted at palliative patients in general. None of the instruments demonstrated satisfactory results for all measurement properties. Fourteen instruments received positive ratings for construct validity. Thirteen instruments were tested for reliability, but only two were tested adequately and had positive results (ICC>0.70). Responsiveness was not tested adequately for any of the instruments. Very few of the studies provided information on the interpretation of the scores. Overall, the MQOL, followed by the QUAL-E and the QODD, received the best ratings for their measurement properties.

Conclusions
Many measurement instruments were identified, but most had not yet been adequately evaluated. The evaluation of existing instruments with good content validity should have priority over the development of new instruments.

Introduction

The interest in palliative care has significantly increased in the past decade. The main focus of palliative care is to improve the quality of life of patients and their families who face the problems associated with a life-threatening illness.[1] Palliative care may entail any form of medical care or treatment that concentrates on the prevention and relief of suffering. Any combination of pain and symptom management, psychological care, and spiritual care, and social support can be applied to improve the quality of life of patients for whom there are no longer any curative treatment options.[2] Palliative care is most commonly associated with cancer patients, but it can be applied to all patients with incurable diseases, for example patients with heart failure, renal disease or neurodegenerative diseases such as multiple sclerosis or amyotrophic lateral sclerosis.

Quality-of-life measurement is an important aspect of palliative care, given that maximizing the quality of life of terminally ill patients is the main aim of this type of care. A large variety of quality-of-life measurement instruments are appropriate for use in palliative care. However, both feasibility (for example the number of questions and the completion time needed) and clinimetric quality varies widely over these instruments. Furthermore, at present there is no agreement on how quality of life should be measured, or which is the best instrument to use. Consequently, many different quality-of-life questionnaires are used, and new ones continue to be developed. We felt the need to determine which are adequate instruments, in order to facilitate decision making with regard to the most appropriate instruments for use in research or clinical practice.

A variety of earlier reviews have identified quality-of-life measurement instruments that are appropriate for use in palliative care.[3-10] However, none of these reviews could serve as a guide for the adequate and comprehensive choice of a questionnaire for research or clinical practice. First of all, because many reviews[4, 7, 9] have focused on instruments that have been specifically designed for cancer patients, whereas quality-of-life measurement in patients with other terminal diseases is also of great significance. Furthermore, Jordhoy et al.[5] recently published a review of quality-of-life measures, but they focused on the aspect of physical functioning only. Mularski et al.[10] reviewed not only quality-of-life instruments, but all measures of end-of-life care, including instruments to measure satisfaction and the quality of the care, caregiver well-being, grief and bereavement. Additionally, most reviews could possibly have missed some studies which focused on domain-specific instruments, because the reviewers searched for instruments measuring overall quality-of-life. In particular, spirituality-specific instruments could have been missed, because spirituality has only recently been considered to be important for the quality of life of terminally ill patients.[11, 12] As a consequence, spirituality is somewhat under represented in several quality-of-life measurement instruments. Moreover, all of the reviews[3-10] described the content and measurement properties of the instruments, but none had a rating list with explicit criteria assessing measurement properties. Therefore, it remains difficult to compare the quality of various measurement instruments, and to determine what a good, or the best questionnaire is, given any combination of measurement purpose and patient group.

The purpose of the present study was to make an inventory of all currently available quality-of-life measurement instruments that are suitable for the use in palliative care and to assess the content and clinimetric quality of these instruments. This can help investigators and clinicians in their choice or an adequate measurement instrument that is applicable in palliative care.

Methods

Selection of the measurement instruments

We searched PubMed, Embase, CINAHL and PsycINFO for relevant literature in the English and Dutch language (January 1990 to April 2008). The following keywords were used to identify eligible studies: palliative care, terminal care, hospice care, end-of-life, and quality of life (MESH term or text word), combined with a search filter for clinimetric studies. Because spirituality is somewhat under represented in a number of quality-of-life instruments, we added two search terms: 'religion and psychology' (MESH term) and spiritual (text word). Appendix 1 presents a detailed overview of the search strategy. All abstracts were reviewed by one reviewer to assess whether the study was eligible for inclusion in the review. We applied the following inclusion criteria: 1) the study should describe the development or validation of a measurement tool; 2) the measurement instrument should measure (at least one domain of) quality of life in a population of patients for whom there are no further curative treatment options; 3) the study should have investigated at least one measurement property of the instrument; 4) the measurement instrument should have been validated in a English or Dutch population. We excluded studies concerning instruments that are intended to measure the quality of and/or satisfaction with palliative care. Studies published as a clinical trial, case-report, editorial, bibliography or review were also excluded. If there was any uncertainty about inclusion, eligibility was assessed by two reviewers based on the full text of the article.

Data-extraction

Data were extracted from the articles for the description of the instrument characteristics and the quality assessment by two independent reviewers (GA and one of the other authors). The results of the data-extraction and the ratings for the clinimetric characteristics were compared, and any disagreements between the reviewers were discussed and resolved in consensus meetings. If necessary, any remaining disagreement was resolved by a third reviewer (HCWdV or MAE). The quality assessment ratings were based on the quality criteria for measurement properties defined by Terwee et al.[13] and the preliminary version of the 'COnsensus-based Standards for the selection of health status Measurement INstruments' COSMIN.[14]

Instrument characteristics

The descriptive data extracted from the studies included: a) the target population; b) the quality of life domains the instrument is intended to measure; c) the number of items; d) the number of response options; e) the scoring algorithm (e.g. sub scale scores and/or total score); f) the recall period; g) the time needed to complete a questionnaire; h) the mode of administration (e.g. [proxy] self-report or interview); and i) whether the full text of the instrument is available. These aspects describe the design, content and application of measurement instruments, and provide clinicians and researchers with information which could help them to decide which instruments may be appropriate and/or feasible for a particular study or setting.

Measurement properties

Measurement properties convey information about the clinimetric quality of a measurement instrument, and can guide researchers and clinicians in making a choice between various potentially appropriate instruments. We rated content and construct validity, internal consistency, reliability, responsiveness and interpretability. The quality criteria will be described in more detail below (see also Appendix 2).

Validity

Validity refers to the extent to which an instrument measures what it is intended to measure.[15] The instruments were evaluated for both content and construct validity. Content validity refers to the degree to which the domains of interest are represented by the items in the questionnaire.[16] These items must reflect aspects that are important to patients for whom there are no further curative treatment options. Therefore, the involvement of patients in the item selection is a requirement, in combination with reference to the literature or consultation with experts. There should be a clear description of the measurement aims, the target population and the item selection. Lastly, the full text of the instrument must be available to achieve a positive rating.

Construct validity refers to the extent to which the scores for a particular instrument correspond to other measures in a manner that is consistent with theoretical expectations concerning the constructs that are measured.[17] Construct validity should be assessed by testing predefined hypotheses (e.g. about expected correlations between (scales of) a questionnaire and another comparable instrument). A positive rating is achieved if the hypotheses are specified in advance and at least 75% of the hypotheses are confirmed.

Internal consistency: Internal consistency is a measure of the extent to which items in a questionnaire (sub) scale are correlated, thus measuring the same construct. Factor analysis should be applied to determine the homogeneity of items in a (sub) scale. To determine the internal consistency Cronbach's alpha should be calculated for each (sub) scale separately. A positive rating is achieved when factor analysis is performed in an adequate study size (7* number of items AND > 100) and Cronbach's alpha for each sub scale is between 0.70 and 0.90. Note that Cronbach's alpha is only relevant if the instrument is based on a reflective model. In a reflective model, the construct to be measured is reflected in the items, in contrast to a formative model, in which the items are causal and form the construct to be measured.[18]

Reliability

Reliability concerns the degree to which repeated measurements in stable persons provide similar results. The time-interval between two measurements needs to be short enough to ensure that no change in quality of life has to be occurred and long enough to prevent recall bias. A time-interval of 1 week was considered to be appropriate for terminally ill patients.

We assessed the test-retest reliability and the absolute measurement error. Reliability refers to the extent to which the instrument is able to distinguish patients from each other, despite measurement error. Reliability was assessed as positive if an intraclass correlation coefficient (ICC) or Kappa of at least 0.70 was calculated for each domain.

Absolute measurement error, measuring lack of agreement, estimates the absolute difference between two repeated measurements, and is expressed in the dimension of measurement. The standard error of measurement (SEM), or the smallest detectable change (SDC) are adequate measures of absolute measurement error. The SDC must be smaller than the minimal important change (MIC), or the MIC must be outside the limits of agreement (LOA) to score a positive rating. Because the MIC value is a relatively new approach, and not yet widely known, a positive rating is also given if the authors have provided convincing arguments that the measurement error was acceptable. In both the evaluation of test-retest reliability and measurement error, the sample size must be at least 50 patients.

Responsiveness

Responsiveness refers to the ability of an instrument to detect important change over time in the concept being measured.[19] The evaluation of responsiveness requires predictions about how the results of the questionnaire should correlate with other related measurements. Therefore, responsiveness is rated as positive if hypotheses about the relationship between change in the instrument and corresponding changes in reference measurements were specified in advance. A positive rating is also given if the instrument is able to distinguish clinically important change from measurement error. Therefore, responsiveness must be tested by relating the SDC to the MIC, as described under measurement error.

Interpretability

Interpretability is defined as the degree to which (change) scores on an instrument can be interpreted. Mean scores and standard deviations should be reported for at least 4 relevant (sub) groups of patients. In addition, the authors must provide information about what (difference in) score would be clinically meaningful, and no floor or ceiling effects must be present. Floor and ceiling effects were considered to be present if more than 15% of the respondents achieved the highest or lowest possible score. If all the above mentioned requirements are met, interpretability is rated as positive.

Scoring of the measurement properties

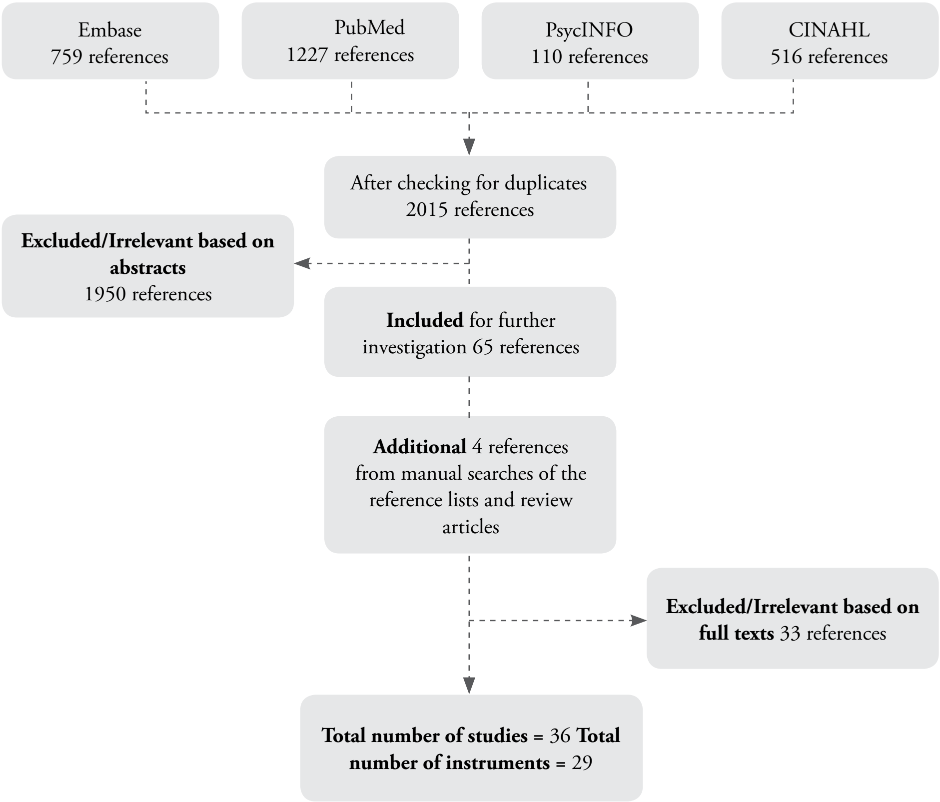
For each of the above mentioned measurement properties the following rating options were used: 0 = not done, = low quality, ? = indeterminate and + = high quality. Validity, reliability and responsiveness depend on the setting and the population in which they are assessed. Therefore, descriptions of the characteristics of the study population, measurements, setting and data analysis of every individual clinimetric study were rated. If a description was lacking or methodological weaknesses were found, the clinimetric property was rated as indeterminate.

Results

Selection of studies

The search strategy yielded a total of 2015 hits (Figure 1). The titles and abstracts were screened, excluding 1950 references as irrelevant according to the inclusion and exclusion criteria described in the Methods section. The main search was supplemented by manual searches of the reference lists of the retrieved articles, which yielded four additional articles. Of the 69 full-text articles we studied, 36 met the inclusion criteria. Most of the excluded studies concerned quality-of-life instruments, but the evaluation of the measurement properties was not described.[20-28] Other studies were excluded because of an irrelevant study population, for example a curative patient population,[29-35] or because the aim of the study was not to develop or validate an instrument but, for example, to compare different questionnaires,[36-44] or because the instrument that was validated was not available in English or Dutch.45-48 Another reason for exclusion was that the instrument was intended to measure the quality of the care or satisfaction with the care.[49-52] Finally, a total of 36 studies concerning 29 questionnaires were included in this review.

Figure 1 Results of search strategy



Instrument characteristics

Table 1 presents a description of the 29 instruments (full names are given in Appendix 3). More than half of the questionnaires were specifically developed for palliative care patients in general, but several questionnaires were designed for cancer patients, and two for hospice patients. The PNPC had the most items (n=138), followed by the NA-ACP (n=132), while the MQOL-CSF (n=8) and the PAQ (n=4/9) had the least items. The Emanuel and Emanuel medical directive could take two or three hours to complete, whereas the PDI, the CMSAS and the ESAS all take about two to five minutes to complete. Most of the instruments are self-report questionnaires, designed to be completed by the patient. The POS has two almost identical versions, a patient version and a staff version. Five other questionnaires could be completed by either the patient or a proxy. The Emanuel and Emanuel medical directive, the MRDI, the QODD and the QUAL-E are interview-based questionnaires. The SEIQoL[53] is not included in the tables because it differs from the other instruments with regard to the mode of administration (semi-structured interview) and the nature of the generated data (individual, patient-generated scores and dimensions). Therefore, the categories that apply to all other instruments presented in the tables do not apply to the SEIQoL.

Table 1 Description of the Instruments

Instrument	Target population	Domains[a]	Number of Items	Number of response options	Scoring algorithm	Recall period[b]	Completion time	Self-report / proxy / interview	Full copy of instrument available
BHI [55]	Hospice patients	Symptoms; QoL[a]	17	11	---	No / Few days / Week	9 min.	Self-report[c]	Yes
CAMPAS-R [56]	All kind of palliative care patients	Presence and interference of physical and psychological symptoms	2 x 10	VAS	Subscale	Week	---	Self-report	Yes
DS [57]	Cancer patients	Loss of meaning; Dysphoria; Disheartenment, Helplessness; Sense of failure[a]	24	5	Subscale and total	2 weeks	---	Self-report	Yes
EFAT [58, 59]	Cancer patients	Symptoms and functions	11	4	Total	No	---	Proxy	Yes
Emanuel and Emanuel Medical Directive [60]	Severely ill patients	*Patient-generated*	48	---	Not applicable	Not applicable	2-3 hours	Structured interview	No
EORTC QLQ-OES18 [61]	Oesophageal cancer patients	Dysphagia; Eating restrictions; Pain; Reflux; 6 single items	18	4	Subscale	1 week	15 min. (incl. completion of EORTC QLQ-C30)	Self-report	Yes
EORTC QLQ-STO22 [62]	Patients with adenoma carcinoma of the stomach	Dysphagia; Eating restrictions; Pain; Reflux; Anxiety; 3 single items	22	4	Subscale	1 week	15 min (incl. completion of EORTC QLQ-C30)	Self-report	Yes
ESAS [63]	Palliative care patients	Symptoms	10	VAS 10	Total	No	5 min.	Self-report	Yes
FACIT-Pal [64]	Patients with life limiting illness	Symptoms; Family and friend relationships; Life closure issues; Decision making and communication abilities	19	5	Total	7 days	---	Self-report	Yes
HQLI [65, 66]	Hospice patients	Psychophysiological; Functioning; Social/spiritual[a]	28	11	Subscale and total	---	10-15 min.	Self-report	No
LCS [67]	Terminally ill patients	Self-reconciled; Self-restructuring[a]	20	5	Subscale and total	---	---	Self-report	Yes

Instrument	Target population	Domains[a]	Number of Items	Number of response options	Scoring algorithm	Recall period[b]	Completion time	Self-report / proxy / interview	Full copy of instrument available
LEQ [68]	People with incurable cancer	Freedom; Appreciation of life; Contentment, Resentment; Social Integration[a]	44	7	Subscale	---	---	Self-report	No
MQLS [69]	Palliative care patients	Physical; Cognition; Social; Energy; Role; Rest; Function; Emotion	32	7	---	24 hours	3-30 min.	Self-report[c]	Yes
MQOL [70, 71]	People with life threatening illness	Psychological symptoms; Existential well-being; Support; Physical symptoms[a]	16	11	Subscale and total	2 days	10-30 min.	Self-report	Yes
MQOL-CSF [72]	Terminally ill patients	Global QoL; Physical symptoms; Psychological; Existential	8	11	Subscale and total	2 / 7 days	3.26 min	Self-report	No
MRDI [73]	Terminally ill patients	Physiological; Psychological; Sociological; Spiritual	28	VAS	Total score	---	---	Structured interview[c]	No
MSAS [74, 75]	Cancer patients	Global distress; Physical; Psychological[a]	32	4 / 5	Subscale and total	1 week	20 – 60 min	Self-report / Proxy	Yes
CMSAS [76]	Cancer patients	Physical and psychological symptoms	14	4 / 5	Subscale and total	7 days	2-4 min.	Self-report	Yes
MSAS-GDI [77]	Cancer patients	Psychological symptoms; physical symptoms	11	4	Total	Last week of life	---	Proxy	Yes
MVQOLI-R [78, 79]	Terminally ill patients	Symptoms; Function; Interpersonal; Well-being; Transcendence	25	5	Subscale and total	No	---	Self-report[c]	Yes
NA-ACP [80]	Advanced cancer patients	Medical communication/information; Psychological/emotional; Daily living; Financial; Symptom; Spiritual; Social	132	5	Subscale	4 months	76 min.	Self-report	No
PAQ [81]	Palliative cancer patients	Autonomy	4 / 9	3	Total	----	---	Self-report	No
PDI [82]	Patients nearing the end of life	Symptom distress; Existential distress; Dependency; Peace of mind; Social support[a]	25	5	---	Few days	2 min. (max. 10-15 min.)	Self-report	Yes
PNPC [83]	Palliative care patients	ADL&IADL; Physical Symptoms; Role activities; Financial; Social; Psychological; Spiritual; Autonomy; Informational Needs; Quality-of-Care aspects	138	3	Subscale	No	---	Self-report	Yes
PNPC-sv [84]	Palliative care patients	ADL&IADL; Physical Symptoms; Financial; Social; Psychological; Spiritual; Autonomy; Informational needs	33	3	Subscale	No	---	Self-report	Yes
POS [85]	Advanced cancer patients & staff	Physical; Psychological; Spiritual	Patient: 10 Staff: 12	3 / 4 / 5	---	3 days	patients 6.9 min. staff 5.7 min.	Self-report / Proxy	Yes
QODD [86]	Family members of terminally ill patients/ health care workers	Symptoms and personal care; Preparation for death, Moment of death; Family; Treatment preferences; Whole person concerns	31	11	Total	Retrospective	---	Structured proxy interview	Yes
QUAL-E [87]	Seriously ill patients	Life completion; Relationship with health care provider; Preparation[a]	26	5	Subscale and total	1 week / 1 month	---	Structured interview	Yes
SNI [88]	Patients near the end of life	Outlook; Inspiration; Spiritual activities; Religion; Community[a]	17	5	Subscale and total	---	---	Self-report	Yes

[a] Domains are the same as factors determined by factor analysis
[b] When several recall periods are reported, the recall period differs over items
[c] Administration by proxy possible
--- = no information available

Measurement properties

Table 2 presents the published clinimetric data concerning the identified questionnaires. The ratings of the measurement properties that were assigned to the instruments are shown in Table 3. None of the instruments included in our review had been adequately tested for all measurement properties on the rating list.

The MQOL had the best clinimetric quality rating, followed by the QUAL-E and the QODD. All these questionnaires have good content validity, construct validity and internal consistency, but only the MQOL has good reliability. Information on responsiveness, absolute measurement error and interpretability was lacking or insufficient for the MQOL, the QUAL-E and the QODD.

Table 2 Identified Instruments with Published Clinimetric Data

Measure (reference)	Study population	Validity	Internal consistency	Reliability	Responsiveness
BHI [55]	Hospice patients	Overall symptom scores correlates with quality of life scores for patients (r=0.71, p<0.001)	Cronbach's α of the 2 subscales: 0.88; 0.94	Tested by paired sample t-test: 0.58-0.63 (time interval: ± 1 wk)	---
CAMPAS-R [56]	Palliative home care patient (estimated to be in their last year of life)	Pain severity and interference scores on CAMPAS-R correlated significantly with corresponding scores on BPI and EORTC (r=0.82-0.88); All other physical severity and interference symptom scores on CAMPAS-R correlated also significantly with the EORTC (r=0.31-0.91); Patient anxiety and depression strongly correlated with corresponding scores on HADS and EORTC (r=0.55-0.66 resp. r=-0.67- -0.77)	Cronbach's α severity: 0.77; Cronbach's α interference: 0.80	---	Predefined hypotheses were tested: CAMPAS-R could differentiate between patients who were near vs. less near to death (cut-off point: 60 days)
DS [57]	In patients with cancer	Total scores and subscales significantly correlates with the McGill QOL, BDI, PHQ, Beck's measure of hopelessness, and SAHD to measure desire for hastened death; Demoralization differentiates from depression	Cronbach's α: 0.70-0.89	---	---
EFAT [5]	Cancer patients from a palliative care unit	Predefined hypotheses were tested: EFAT scores increase from admission to discharge: *confirmed;* EFAT scores are both higher at admission and discharge for patients remained until death or transferred to another institution than for patients discharged home: *confirmed*; Correlated with KPS (r=-0.79, p=0.001), ECOG (r=0.85, p=0.0001) and global PS rating (r=0.90, p=0.0001); Correlations for 7/10 EFAT items to total score ranged from r=0.62-0.95	---	---	---
EFAT-2 [59]	Cancer patients from a palliative care unit	Predefined hypotheses were tested: Patients transferred to hospice have higher scores (poorer functional status) than patients discharged home: *confirmed;* All correlations between items were ≥0.3 except the pain item which not correlated with any other item	Cronbach's α: 0.86	---	---
Emanuel and	In patients with progressive,	Predefined hypotheses were tested: Hospice patients decided	Cronbach's α across	ICC across treatments by	Small effect size for change in

Measure (reference)	Study population	Validity	Internal consistency	Reliability	Responsiveness
Emanuel Medical Directive[60]	chronic and life-threatening illness and a prognosis between 6 wks and 3 yrs (dialysis clinics; rehabilitation hospitals; long-term facilities)	more frequently to forego curative or aggressive life-sustaining treatments: *confirmed;* Consistently lower preference scores across situations for those with goal "comfort care" vs "prolong life" (p<0.0001)	treatments by scenario: 0.80–0.85 Cronbach's α across scenarios by treatment: 0.86–0.90	scenario: 0.69–0.75 ICC across scenarios by treatment: 0.60–0.79 (time interval: 21 days)	preferences as a function of health status change (patients with worsened health status, want less intervention, whereas those improved health want more intervention)
EORTC QLQ-OES18[61]	Patients with oesophageal squamous cell or adenocarcinoma	Predefined hypotheses were tested: Correlation of >0.40 between items and its own scale: *confirmed;* A higher correlation between an item and its own scale than with another scale: *confirmed;* No correlation between EORTC QLQ-OES18 scales and generic aspects of QoL unless they address similar themes: *confirmed;* EORTC QLQ-OES18 could differentiate between curative and palliative patients in several functional and symptoms scales; Could differentiate between surgery patients and chemoradiation patients	Cronbach's α: 0.61-0.75	---	EORTC QLQ-OES18 could demonstrate treatment-induced changes over time
EORTC QLQ-STO22[62]	Patients with gastric cancer	Predefined hypotheses were tested: Correlation of >0.40 between items and its own scale: *confirmed;* A higher correlation between an item and its own scale than with another scale: *confirmed* EORTC QLQ-STO22 could differentiate in several scales and items between palliative and curative patients and between patients with Karnofsky scores <80 and >80	Cronbach's α: 0.72-0.80	---	The reflux scale demonstrated sensitivity to changes in weight loss over time; Dysphagia, pain, reflux and eating were sensitive to changes in observer-rated dysphagia scores; Could demonstrate treatment-induced changes over time
ESAS[63]	In and out patients with cancer	ESAS distress score correlated most closely with physical symptom subscales in the FACT and MSAS and with KPS	Cronbach's α of the overall ESAS: 0.79	Spearman's test-retest correlations: 0.86 (p<0.0001); 0.45 (p<0.05) (time interval: resp. 2 days; 1 wk)	---
FACIT-Pal[64]	Cancer patients	Predefined hypotheses were tested : Patients died within 3 months and patients lived ≥ 1 year differ significantly on the FACT-G subscales and FACIT-Pal: *confirmed;* Patients with KPS score ≥80 have higher QoL than patients with KPS ≥70: *confirmed*; Overall QoL and physical, functional and palliative subscales correlates with symptom intensity and depression: *confirmed*	Cronbach's α: 0.75-0.85	---	---
HQLI[65]	Hospice home care patients with cancer	Predefined hypotheses were tested: A weak significant correlation with ECOG-PSR: *confirmed;* HQLI could differentiate between patients and non patients: *confirmed*	Cronbach's α: 0.82-0.85	---	---
HQLI[66]	Hospice home care patients with end-stage cardiac disease	Predefined hypotheses was tested: A weak-to-moderate negative correlation with the MSAS global symptom distress score: *confirmed;* Significant correlation between HQLI psychopsychological well-being scale and MSAS (r=-0.45, p=0.012)	Cronbach's α of the overall HQLI: 0.78	---	---
LCS[6]	Hospice patients diagnosed with cancer; AIDS; ALS; end-stage system diseases	Correlated with the total score as well as with the subscales of the Affect Balance Scale	Cronbach's α for 2 subscales: 0.80; 0.82	---	---
LEQ[68]	Cancer patients from outpatient clinics; hospital wards	Correlated with RSC: 0.01-0.62 (<0.01 only for resentment, freedom and social integration); Correlated with MacAdam and Smith: 0.02-0.62 (<0.01 only for resentment, freedom and social integration)	Cronbach's α: 0.70-0.85	Product-moment correlations: 0.77-0.92 (time interval: 48-72 h)	---
MQLS[69]	In and out, and community-based patients	Predefined hypotheses were tested: Correlation with the Spitzer Quality of Life Index: *Confirmed;* Patients able to rate the MQLS themselves rated QoL higher than those who needed assistance: *Confirmed;* Correlation with length of time until death and not with age / sex of the patient: *Confirmed;* Non-symptom-related aspects of QoL are lower among those within 3 weeks of death than among survivors, while symptom ratings would be more similar: *Confirmed*	Cronbach's α for patients: 0.09-0.69 (all nonphysical items combined: 0.79; overall scale: 0.8) Cronbach's α for family: 0.21-0.63 (all nonphysical items combined: 0.84; overall scale: 0.87)	r= 0.63, CI=0.45-0.77 (time interval: 1 wk)	Patients were asked if a change had occurred in QoL since the first rating, 1 wk before: Sensitive to changes in patient's QoL (F=5.26, df=2.53, p=0.01)

Measure (reference)	Study population	Validity	Internal consistency	Reliability	Responsiveness
			Cronbach's α for staff: 0.50-0.78 (all nonphysical items combined: 0.88; overall scale: 0.89)		
MQOL[70]	Patients from palliative care inpatient units (hospital)	Predefined hypotheses were tested: Global measure of QoL (single item) correlates higher MQOL total score than with Spitzer QLI: *confirmed*; MQOL physical measures correlates most highly with Spitzer QLI activity, daily living, health items: *not confirmed*; MQOL psychological subscale correlates most highly with Spitzer QLI health, outlook items: confirmed; MQOL existential subscale correlates most highly with any Spitzer QLI outlook item: *confirmed*; MQOL support subscale correlates most highly with the Spitzer QLI support item: *confirmed*	Cronbach's α: >0.70 except physical subscale (0.62)	---	---
MQOL[71]	Cancer patients from oncology day centre, receiving chemotherapy; palliative home care service	---	---	ICC: 0.62-0.85 (time interval: 2 days)	Patients ranked their days as good, average, or bad: Pearson correlations: MQOL-change score: 0.56 (existential) - 0.66 (total), except for support scale (0.13); Effect sizes: largest for differences between good/bad days; moderate between bad/average days; average/good days, except for physical resp. support scale
MQOL-CSF [72]	Patients from hospice centre (reliability test); hospital inpatient wards (validity test)	Predefined hypothesis were tested: High correlation with MQOL-CSF items: *confirmed* (0.48-0.73); Strong correlations (>0.40) between MQOL-SCF items and their own domains: *confirmed* (4/7); Items correlates strongest with their own domain: (6/7);Weak correlation with SF-36 general health question:	Cronbach's α: 0.64-0.81, except existential domain (0.46)	Spearman's test-retest correlations: 0.5-0.86 (time interval: 1 wk)	---

Measure (reference)	Study population	Validity	Internal consistency	Reliability	Responsiveness
		confirmed (0.18-0.40); Low haemoglobin levels are associated with lower MQOL-CSF scores: *confirmed*			
MRDI [73]	Hospice patients	Correlated with overall readiness for death question (r=0.45, p<0.01); Correlation between the scores of patients and primary caregivers (r=0.35, p<0.05); between patients and primary hospice nurses (r=0.53, p<0.01); Significant mean difference between terminally-ill and non-terminally cardiac-impaired patients (t=2.76, p<0.01)	Cronbach's α of the overall MRDI: 0.59 (holistic measure)	Test-retest reliability: r(12)=0.22, p=0.22 (low because n=70) (time interval: 7-14 days)	---
MSAS [74]	Advanced cancer and AIDS patients and their family caregivers actively involved in their care	Moderate-to-strong correlations between the GDI and physical and psychological symptoms (range, 0.58-0.81, p=0.002) as well as moderate correlations between physical and psychological symptoms (range, 0.47-0.60, p=0.001) for all patients and caregivers groups	Cronbach's α AIDS patients; caregivers: 0.78-0.87; 0.86-0.91 Cronbach's α Cancer patients; caregivers: 0.78-0.83; 0.81-0.86	---	---
MSAS (FC) [75]	Family caregivers of cancer patients	Inter-item correlation was r=0.45 on psychological scale; r=0.30 on physical scale; r=0.35 on MSAS-GDI; Item-scale correlation was r=0.60 on psychological scale; r=0.50 on physical scale; r=0.54 on MSAS-GDI; Correlations between patients' ratings (regarded as gold standard) and family caregivers' ratings: Kappa=0.22-0.70 physical subscale; Kappa=0.16-0.48 psychological subscale; ICC=0.68 physical subscale; ICC=0.32 psychological subscale; ICC=0.82 MSAS-GDI	Cronbach's α: 0.82-0.84	---	---
CMSAS[76]	In and out cancer patients	Subscales correlated significantly with FACT-G subscales (-0.61- -0.76), KPS (-0.31- -0.64), and MSAS-SF (0.89-0.93)	Cronbach's α: 0.72-0.85	---	---
MSAS-GDI [77]	Family members of cancer patients died in hospital, involved in the decedent's care and decision making in the final month of life	Item-total correlation: r=0.49; Average inter-item correlations: r=0.30; Higher MSAS-GDI scores correlates with discomfort on a single-item indicator (r=0.26, p= 0.02); and with dissatisfaction with help from other family members on a single-item indicator (r=-0.21, p=0.05)	Cronbach's α of the overall MSAS-GDI: 0.82	---	---

Measure (reference)	Study population	Validity	Internal consistency	Reliability	Responsiveness
MVQOLI [78]	Hospice patients	Correlated with MQOLS-CA2, Pearson correlation coefficient: 0.63; MVQOLI total score correlated with a global QoL rating (0.43); Low correlation with KPS (0.19)	Cronbach's α of the overall MVQOLI: 0.77	---	---
MVQOLI-R [79]	Patients from dialysis clinics; hospices; long-term care facilities	Predefined hypotheses were tested: Moderately high correlations with measures of psychological well-being, global symptom-related distress and global QoL but weak with mood and total symptom burden; *not confirmed*	Cronbach's α: 0.23-0.70 Factor analysis showed a heterogeneous structure, items were not effect indicators, but causal indicators	ICC: 0.59-0.77 (time interval: 3-5 days)	Predefined hypotheses were tested: Lower levels of MVQOLI-R are associated with worse global symptom related distress, independent of changes in mood: *confirmed*
NA-ACP [80]	Advanced, incurable cancer patients, not currently receiving formal palliative care	---	Cronbach's α: 0.79-0.98	Test-retest reliability: ICC: 0.67-0.93 Agreement: K: 0.18-0.83 (K=0.4-0.2 for 28 of 132 items) (time interval: 1 wk)	---
PAQ [81]	Cancer patients	Predefined hypotheses were tested: Moderate to high correlations with EORTC QLQ-C30 and COOP-WONCA: *confirmed*; Scoring in the highest quartile of the PNPC is associated with more autonomy problems compared to scoring in the lowest quartile; *confirmed*	Cronbach's α of the 9-item version: 0.86 Cronbach's α of the 4-item version: 0.71	---	---
PDI [82]	In patients receiving palliative care	Predefined hypotheses were tested: The symptom distress scale correlates significantly with all ESAS items except for activity; and with will to live, the General Well-Being scale, the Beck Depression Inventory and the single-item measure of suffering: *confirmed*; The existential distress scale correlates with measures of depression, suffering, well-being, quality of life, satisfaction with quality of life, but not with will to live and loss of dignity: *confirmed*; The dependency scale correlates with activity, ability	Cronbach's α: 0.63-0.83	Test-retest reliability: r=0.85 for the full PDI; r=0.37-0.76 with individual variables	---

Measure (reference)	Study population	Validity	Internal consistency	Reliability	Responsiveness
		to work, rating and satisfaction with quality of life and sense of dignity: *confirmed*; The peace of mind scale correlates only with anxiety, the Beck Depression Inventory and FACIT inner peace factor, but not with will to live, suffering, well-being, rating and satisfaction with quality of life, FACIT total, faith/spirituality and meaning and spirituality factors: *not confirmed;* The social support scale correlates with availability of, and satisfaction with support: *confirmed*			
PNPC [83]	Cancer patients, living at home	Predefined hypotheses tested: Substantial correlation with related quality of life dimensions of EORTC QLQ-C30 and COOP-WONCA: *confirmed*	Cronbach's α: 0.67-0.89 (problem aspect)	---	---
PNPC-sv [84]	Cancer patients, living at home	Predefined hypotheses tested: Correlation (ρ>0.80) with corresponding dimensions in the original PNPC: *confirmed* (ρ: 0.83-0.98); Correlation (ρ>0.40) with corresponding HRQoL dimensions of the EORTC QLQ-C30 and COOP-WONCA: *confirmed*	Cronbach's α: 0.61-0.86 (problem aspect)	---	---
POS [85]	Patients from centres providing palliative care, including inpatient, outpatient, day, home and primary care	Predefined hypotheses tested:Patient version correlates with EORTC QLQ-C30 (physical symptoms, all non QoL problems, QoL): *confirmed (*ρ=0.43-0.53*)*; Staff version correlates with STAS (physical symptoms, all non QoL problems, QoL): *confirmed (*ρ*=0.51-0.80)*	Cronbach's α patient version: 0.65 Cronbach's α staff version: 0.70	Kappa: 0.08-0.62 (time interval was dependent on nature of service providing care)	Change over time was not statistically significant
QODD [86]	Dying patients	Predefined hypothesis tested: Higher QODD-scores correlates with death at home, death in location patient desired, lower symptom burden, better ratings for symptom treatment, adherence to patients preferences for end-of-life care, compliance with treatment preferences, family satisfaction regarding communication with health care team, availability of health care team member at night/weekends: *confirmed*	Cronbach's α for overall QODD 0.89 Factor analysis did not support subscale construction		
QUAL-E [87]	Patients with cancer,	Predefined hypotheses were tested: Strong correlation (>0.60)	Cronbach's α: 0.68-	Test-retest reliability:	

Measure (reference)	Study population	Validity	Internal consistency	Reliability	Responsiveness
	congestive heart failure, end stage renal disease, chronic obstructive pulmonary disease	between FACIT-SP spiritual well-being subscale and QUAL-E: *confirmed;* Moderate correlation (0.4-0.6) between QUAL-E completion and preparation subscale and FACIT-SP: *confirmed;* Moderate associations between QUAL-E and MVQOL's similar domains: *confirmed;* Moderate correlation between first two PDM items and QUAL-E health care subscale: *confirmed;* Correlations among QUAL-E subscales and no relationships among unrelated subscales and weak to moderate correlations among related scales or those with conceptual overlap: *confirmed*	0.87	*r*: 0.61-0.74 except for symptoms *r*: 0.23	
SNP [88]	Patients from outpatient hospices and one inpatient hospice facility	Predefined hypotheses was tested: The number of unmet needs correlates with life satisfaction as measured by a Cantril ladder: *Confirmed: -0.17;* Item-to-total correlations: 0.33-0.70	Cronbach's α:0.62-0.78	---	---

--- no data published

Table 3 Rating of Measurement Properties of the Instruments

Instrument	Content validity	Construct validity	Internal consistency	Reliability	Absolute measurement error	Responsiveness	Interpretability
BHI [55]	?	0	+	?	0	0	0
CAMPAS-R [56]	+	?	?	0	0	?	0
DS [57]	?	?	?	0	0	0	0
EFAT[58]	+	+	0	0	0	0	0
EFAT-2 [59]	+	?	+	0	0	0	0
Emanuel and Emanuel Medical Directive [60]	?	?	?	-	0	?	?
EORTC QLQ-OES18 [61]	+	?	-	0	0	?	?
EORTC QLQ-STO22 [62]	+	?	+	0	0	?	?
ESAS [63]	?	?	?	?	0	0	0
FACIT-Pal [64]	?	+	?	0	0	0	0
HQLI [65]	?	+	+	0	0	0	0
HQLI (in end stage cardiac disease patients) [66]	?	+	?	0	0	0	0
LCS [67]	?	?	?	0	0	0	0
LEQ[68]	?	?	?	?	0	0	?
MQLS [69]	+	+	?	?	0	?	0
MQOL [70, 71]	+	+	+	+	0	?	0
MQOL-CSF [72]	?	+	?	?	0	0	0
MRDI [73]	?	?	?	?	0	0	0
MSAS [74]	+	0	?	0	0	0	0
MSAS (FC) [75]	+	?	?	0	0	0	0
CMSAS [76]	+	?	?	0	0	0	0
MSAS-GDI [77]	+	0	+	0	0	0	0
MVQOLI [78]	+	+	0	0	0	0	0
MVQOLI-R [79]	+	?	-	?	0	?	0
NA-ACP [80]	?	0	?	+	?	0	0
PAQ [81]	?	+	?	0	0	0	0
PDI [82]	?	+	+	?	0	0	0
PNPC [83]	+	+	?	0	0	0	0
PNPC-sv [84]	+	+	?	0	0	0	0
POS [85]	?	?	?	-	0	?	0
QODD [86]	+	+	+	0	0	0	?
QUAL-E [87]	+	+	+	?	0	0	0
SNI [88]	+	?	?	0	0	0	0

Method or result was rated as: + high quality; ? indeterminate; - low quality; 0 no data available

Discussion

Our review identified 29 questionnaires to assess the quality of life of palliative care patients, of which 7 were revised versions of the original instruments. The characteristics and the clinimetric quality of the instruments varied substantially. None of the instruments achieved satisfactory ratings for all categories. Overall, the MQOL received the best ratings for its measurement properties, followed by the QUAL-E and the QODD. These questionnaires are all designed to assess the quality of life of palliative care patients in general, but only the QODD is designed to be completed by family members or health care workers.

Because many measurement properties were not (adequately) tested for a large number of instruments, we describe the shortcomings of the testing below. In order to achieve adequate content validity, the involvement of the target population in the item selection is crucial, because patients are the experts on their own quality of life. The selection of items was inadequately performed for seven of the instruments, mainly because the patients were not involved in the process. Furthermore, 18 questionnaires fulfilled the requirements with regard to content validity .

Studies evaluating construct validity were available for all but four instruments. In all articles except one, construct validity was assessed by correlating the instrument to (sub scales of) other quality-of-life measures, performance scores or symptom distress scores. Nevertheless, 10 instruments scored ‘doubtful’ for construct validity because no hypotheses were formulated, and four other instruments scored doubtful because there was no information about the expected direction or magnitude of the correlation. Furthermore, when reviewing the articles, it is impossible to check whether hypotheses were formulated before the data-analysis was performed.

When developing a questionnaire, the theoretical dimensional structure should be tested with factor-analysis, but this had not been done for six questionnaires included in this study. Another reason for a doubtful rating for internal consistency was an inadequate study size. Moreover, Cronbach’s alpha is positively influenced by the number of items in a sub scale, irrespective of the average correlation among items. Five out of nine questionnaires which were rated positive for internal consistency in this study contained more than 22 items. Furthermore, for almost all questionnaires it was not clear whether the items were based on a reflective model or a causal model.

For 12 instruments a test-retest study was performed, but only two questionnaires met our criteria for good reliability. Several authors calculated a correlation coefficient, but this measure is inadequate because systematic differences are not taken into account. Moreover, because terminally ill patients are rarely stable, it is complicated to determine an adequate time-interval between measurements. A short time-interval (> 1 week) often causes recall bias, but palliative care patients may change with regard to the construct to be measured if the time-interval is more than one week.

All the instruments identified in this review were developed as an evaluative outcome measure. However, the responsiveness of quality-of-life questionnaires is seldom tested. None of the instruments had adequate responsiveness, but this is probably due to the strictness of the criteria for testing responsiveness. Moreover, the MIC and the SDC are relatively new concepts that have received much attention recently. However, a considerable number of quality-of-life instruments were developed and validated before there was consensus on the criteria for testing responsiveness. The same applies to absolute measurement error, which was not calculated for one of the identified questionnaires.

None of the developers of the questionnaires included in this review paid sufficient attention to the interpretability of the outcome scores, which is not remarkable given the strict criteria for interpretability. It is difficult to recruit sufficient terminally ill patients, let alone to recruit four relevant sub groups of patients.

We set high standards for the assessment of measurement properties, and accordingly, many measurement properties were not favorably evaluated. However, ‘doubtful’ or ‘poor’ ratings for the clinimetric characteristics of a questionnaire do not necessarily mean that the questionnaire is inadequate. A doubtful rating should be a motive for further testing and evaluating the measurement properties according to the criteria developed by Terwee et al.[13] Therefore, our intention is not to promote the development of new quality-of-life questionnaires for use in palliative care, but to support further testing of existing instruments with good content validity and to select one or a few which are most appropriate for clinical use and/or research purpose. In order to improve palliative care nationally and internationally, organizations for the promotion and development of palliative care, such as the European Association for Palliative Care (EAPC) or the International Association for Hospice & Palliative Care (IAHPC), should also support further testing of the existing quality-of-life instruments, which would also benefit all researchers working in this field. An important advantage of the use of one or a few well-developed and adequately tested questionnaires is the comparability of research results.

This study has a few limitations. Firstly, many studies were identified by our review, but we can not be sure that we did not miss any. However, the search strategy included a clinimetric search filter with a sensitivity of 90-97% to retrieve clinimetric articles, so it is unlikely that we missed any relevant articles.[54] Furthermore, we checked the references of the articles we included and we also consulted some experts to ensure we had not missed any instruments. Another limitation could be the restriction to the English and Dutch languages. However, because measurement properties are not automatically stable across different languages or cultures, an instrument should be tested in the target population and language, in accordance with the aim of study.

In conclusion, we presented a systematic review of 29 questionnaires which measured (at least one domain of) quality of life applicable in the palliative care setting. Information about practical aspects, such as the burden for the respondent, and the clinimetric quality of these instruments could help clinicians and researchers in their choice of measurement instrument. Apart from the clinimetric quality of the instrument, the purpose of the study also plays a role in the choice of an instrument. If the purpose of the measurement is evaluation, testing for responsiveness is important, and if the purpose of the study is discrimination, reliability testing is of significance. As a consequence, we can not provide an explicit recommendation for the use of one specific instrument. Future research should focus on further testing of these measurement instruments.

Reference List

1. Jocham HR, Dassen T, Widdershoven G, Halfens R. Quality of life in palliative care cancer patients: a literature review. J Clin Nurs 2006 Sep;15(9):1188-95.
2. Stewart AL, Teno J, Patrick DL, Lynn J. The concept of quality of life of dying persons in the context of health care. J Pain Symptom Manage 1999 Feb;17(2):93-108.
3. Bruley DK. Beyond reliability and validity: analysis of selected quality-of-life instruments for use in palliative care. J Palliat Med 1999;2(3):299-309.
4. Hearn J, Higginson IJ. Outcome measures in palliative care for advanced cancer patients: a review. J Public Health Med 1997 Jun;19(2):193-9.
5. Jordhoy MS, Inger RG, Helbostad JL, Oldervoll L, Loge JH, Kaasa S. Assessing physical functioning: a systematic review of quality of life measures developed for use in palliative care. Palliat Med 2007 Dec;21(8):673-82.
6. Kaasa S, Loge JH. Quality-of-life assessment in palliative care. Lancet Oncol 2002 Mar;3(3):175-82.
7. Kirkova J, Davis MP, Walsh D, Tiernan E, O'Leary N, LeGrand SB, et al. Cancer symptom assessment instruments: a systematic review. J Clin Oncol 2006 Mar 20;24(9):1459-73.
8. Massaro T, McMillan SC. Instruments for assessing quality of life in palliative care settings. Int J Palliat Nurs 2000 Oct;6(9):429-33.
9. McMillan SC. Quality-of-Life Assessment in Palliative Care. Cancer Control 1996 May;3(3):223-9.
10. Mularski RA, Dy SM, Shugarman LR, Wilkinson AM, Lynn J, Shekelle PG, et al. A systematic review of measures of end-of-life care and its outcomes. Health Serv Res 2007 Oct;42(5):1848-70.
11. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 2000 Nov 15;284(19):2476-82.
12. Steinhauser KE, Voils CI, Clipp EC, Bosworth HB, Christakis NA, Tulsky JA. "Are you at peace?": one item to probe spiritual concerns at the end of life. Arch Intern Med 2006 Jan 9;166(1):101-5.
13. Terwee CB, Bot SD, de Boer MR, van der Windt DA, Knol DL, Dekker J, et al. Quality criteria were proposed for measurement properties of health status questionnaires. J Clin Epidemiol 2007 Jan;60(1):34-42.
14. Mokkink LB, Terwee CB, Knol DL, Stratford PW, Alonso J, Patrick DL, et al. Protocol of the COSMIN study: COnsensus-based Standards for the selection of health Measurement INstruments. BMC Med Res Methodol 2006 Jan 24;6:2.
15. Lohr KN, Aaronson NK, Alonso J, Burnam MA, Patrick DL, Perrin EB, et al. Evaluating quality-of-life and health status instruments: development of scientific review criteria. Clin Ther 1996 Sep;18(5):979-92.
16. Guyatt GH, Feeny DH, Patrick DL. Measuring health-related quality of life. Ann Intern Med 1993 Apr 15;118(8):622-9.
17. Kirshner B, Guyatt G. A methodological framework for assessing health indices. J Chronic Dis 1985;38(1):27-36.
18. Fayers PM, Hand JH. Causal Variables, Indicator Variables and Measurement Scales: An Example from Quality of Life. Journal of the Royal Statistical Society: Series A (Statistics in Society) Vol. 165, No. 2. (2002), pp. 233-261. 2008.
19. Terwee CB, Dekker FW, Wiersinga WM, Prummel MF, Bossuyt PM. On assessing responsiveness of health-related quality of life instruments: guidelines for instrument evaluation. Qual Life Res 2003 Jun;12(4):349-62.
20. Arraras JI, Kuljanic-Vlasic K, Bjordal K, Yun YH, Efficace F, Holzner B, et al. EORTC QLQ-INFO26: A questionaire to assess information given to cancer patients a preliminary analysis in eight countries. Psycho-Oncology 2007;16(3):249-54.
21. Barresi MJ, Shadbolt B, Byrne D, Stuart-Harris R. The development of the Canberra symptom scorecard: a tool to monitor the physical symptoms of patients with advanced tumours. BMC Cancer 2003 Dec 17;3:32.
22. Groenvold M, Petersen MA, Aaronson NK, Arraras JI, Blazeby JM, Bottomley A, et al. The development of the EORTC QLQ-C15-PAL: a shortened questionnaire for cancer patients in palliative care. Eur J Cancer 2006 Jan;42(1):55-64.
23. Hoekstra J, Bindels PJ, van Duijn NP, Schade E. The symptom monitor. A diary for monitoring physical symptoms for cancer patients in palliative care: feasibility, reliability and compliance. J Pain Symptom Manage 2004 Jan;27(1):24-35.
24. Kearsley JH, Schonfeld C, Sheehan M. Quality-of-life assessment during palliative radiotherapy. Australas Radiol 1998 Nov;42(4):354-9.
25. Lehna C, Seck L, Churches S. Development of an outcome measure to document pain relief for home hospice patients: a collaboration between nursing education and practice. Am J Hosp Palliat Care 1998 Nov;15(6):343-51.
26. Mularski RA, Heine CE, Osborne ML, Ganzini L, Curtis JR. Quality of dying in the ICU: ratings by family members. Chest 2005 Jul;128(1):280-7.
27. Schaafsma J, Osoba D. The Karnofsky Performance Status Scale re-examined: a cross-validation with the EORTC-C30. Qual Life Res 1994 Dec;3(6):413-24.
28. Steel K, Ljunggren G, Topinkova E, Morris JN, Vitale C, Parzuchowski J, et al. The RAI-PC: an assessment instrument for palliative care in all settings. Am J Hosp Palliat Care 2003 May;20(3):211-9.
29. Cella D. The Functional Assessment of Cancer Therapy-Lung and Lung Cancer Subscale assess quality of life and meaningful symptom improvement in lung cancer. Semin Oncol 2004 Jun;31(3 Suppl 9):11-5.
30. Cleeland CS, Mendoza TR, Wang XS, Chou C, Harle MT, Morrissey M, et al. Assessing symptom distress in cancer patients: the M.D. Anderson Symptom Inventory. Cancer 2000 Oct 1;89(7):1634-46.
31. Gaunthier DM, Froman RD. Preferences for care near the end of life: scale development and validation. Research in Nursing & Health 2001 Aug;24(4):298-306.
32. Hollen PJ, Gralla RJ, Liepa AM, Symanowski JT, Rusthoven JJ. Adapting the Lung Cancer Symptom Scale (LCSS) to mesothelioma: using the LCSS-Meso conceptual model for validation. Cancer 2004 Aug 1;101(3):587-95.
33. King M, Jones L, Barnes K, Low J, Walker C, Wilkinson S, et al. Measuring spiritual belief: Development and standardization of a beliefs and values scale. Psychol Med 2006;36(3):417-25.
34. Kruse BG, Heinemann D, Moody L, Beckstead J, Conley CE. Psychometric properties of the Serenity Scale. Journal of Hospice & Palliative Nursing 2005 Nov;7(6):337-44.

35. Schirm V, Sheehan D, Zeller RA. Preferences for Care Near the End of Life: instrument validation for clinical practice. Crit Care Nurs Q 2008 Jan;31(1):24-32.
36. Beadle GF, Yates PM, Najman JM, Clavarino A, Thomson D, Williams G, et al. Illusions in advanced cancer: the effect of belief systems and attitudes on quality of life. Psychooncology 2004 Jan;13(1):26-36.
37. Bjorner JB, Petersen MA, Groenvold M, Aaronson N, hlner-Elmqvist M, Arraras JI, et al. Use of item response theory to develop a shortened version of the EORTC QLQ-C30 emotional functioning scale. Qual Life Res 2004 Dec;13(10):1683-97.
38. Petersen MA, Groenvold M, Aaronson N, Blazeby J, Brandberg Y, de GA, et al. Item response theory was used to shorten EORTC QLQ-C30 scales for use in palliative care. J Clin Epidemiol 2006 Jan;59(1):36-44.
39. Pratheepawanit N, Salek MS, Finlay IG. The applicability of quality-of-life assessment in palliative care: comparing two quality-of-life measures. Palliat Med 1999 Jul;13(4):325-34.
40. Sprangers MA, Cull A, Groenvold M, Bjordal K, Blazeby J, Aaronson NK. The European Organization for Research and Treatment of Cancer approach to developing questionnaire modules: an update and overview. EORTC Quality of Life Study Group. Qual Life Res 1998 May;7(4):291-300.
41. Stockler MR, Osoba D, Goodwin P, Corey P, Tannock IF. Responsiveness to change in health-related quality of life in a randomized clinical trial: a comparison of the Prostate Cancer Specific Quality of Life Instrument (PROSQOLI) with analogous scales from the EORTC QLQ-C30 and a trial specific module. European Organization for Research and Treatment of Cancer. J Clin Epidemiol 1998 Feb;51(2):137-45.
42. Higginson IJ, McCarthy M. A comparison of two measures of quality of life: their sensitivity and validity for patients with advanced cancer. Palliat Med 1994 Oct;8(4):282-90.
43. Higginson IJ, Donaldson N. Relationship between three palliative care outcome scales. Health Qual Life Outcomes 2004;2:68.
44. Lemieux J, Beaton DE, Hogg-Johnson S, Bordeleau LJ, Goodwin PJ. Three methods for minimally important difference: no relationship was found with the net proportion of patients improving. J Clin Epidemiol 2007;60(5):448-55.
45. Llobera J, Esteva M, Benito E, Terrasa J, Rifa J, Pons O, et al. Quality of life for oncology patients during the terminal period. Validation of the HRCA-QL index. Support Care Cancer 2003 May;11(5):294-303.
46. Maunsell E, Allard P, Dorval M, Labbe J. A brief pain diary for ambulatory patients with advanced cancer: acceptability and validity. Cancer 2000 May 15;88(10):2387-97.
47. Miyashita M, Morita T, Sato K, Hirai K, Shima Y, Uchitomi Y. Good Death Inventory: A Measure for Evaluating Good Death from the Bereaved Family Member's Perspective. J Pain Symptom Manage 2008 Mar 19.
48. Mystakidou K, Tsilika E, Kouloulias V, Parpa E, Katsouda E, Kouvaris J, et al. The "Palliative Care Quality of Life Instrument (PQLI)" in terminal cancer patients. Health Qual Life Outcomes 2004;2:8.
49. Carson MG, Fitch MI, Vachon ML. Measuring patient outcomes in palliative care: a reliability and validity study of the Support Team Assessment Schedule. Palliat Med 2000 Jan;14(1):25-36.

50. Casarett D, Pickard A, Bailey FA, Ritchie CS, Furman CD, Rosenfeld K, et al. A nationwide VA palliative care quality measure: The family assessment of treatment at the end of life. J Palliative Med 2008;11(1):68-75.
51. Engelberg R, Downey L, Curtis JR. Psychometric characteristics of a quality of communication questionnaire assessing communication about end-of-life care. J Palliat Med 2006 Oct;9(5):1086-98.
52. Higginson IJ, McCarthy M. Validity of the support team assessment schedule: do staffs' ratings reflect those made by patients or their families? Palliat Med 1993;7(3):219-28.
53. Waldron D, O'Boyle CA, Kearney M, Moriarty M, Carney D. Quality-of-life measurement in advanced cancer: assessing the individual. J Clin Oncol 1999 Nov;17(11):3603-11.
54. Terwee CB, Jansma EP, Riphagen I, de Vet HCW. Development of a methodological PubMed search filter for finding studies on measurement properties of measurement instruments. Submitted 2008.
55. Guo H, Fine PG, Mendoza TR, Cleeland CS. A preliminary study of the utility of the brief hospice inventory. J Pain Symptom Manage 2001 Aug;22(2):637-48.
56. Ewing G, Todd C, Rogers M, Barclay S, McCabe J, Martin A. Validation of a symptom measure suitable for use among palliative care patients in the community: CAMPAS-R. J Pain Symptom Manage 2004 Apr;27(4):287-99.
57. Kissane DW, Wein S, Love A, Lee XQ, Kee PL, Clarke DM. The Demoralization Scale: a report of its development and preliminary validation. J Palliat Care 2004;20(4):269-76.
58. Kaasa T, Loomis J, Gillis K, Bruera E, Hanson J. The Edmonton Functional Assessment Tool: preliminary development and evaluation for use in palliative care. J Pain Symptom Manage 1997 Jan;13(1):10-9.
59. Kaasa T, Wessel J. The Edmonton Functional Assessment Tool: further development and validation for use in palliative care. J Palliat Care 2001;17(1):5-11.
60. Schwartz CE, Merriman MP, Reed GW, Hammes BJ. Measuring patient treatment preferences in end-of-life care research: applications for advance care planning interventions and response shift research. J Palliat Med 2004 Apr;7(2):233-45.
61. Blazeby JM, Conroy T, Hammerlid E, Fayers P, Sezer O, Koller M, et al. Clinical and psychometric validation of an EORTC questionnaire module, the EORTC QLQ-OES18, to assess quality of life in patients with oesophageal cancer. Eur J Cancer 2003 Jul;39(10):1384-94.
62. Blazeby JM, Conroy T, Bottomley A, Vickery C, Arraras J, Sezer O, et al. Clinical and psychometric validation of a questionnaire module, the EORTC QLQ-STO 22, to assess quality of life in patients with gastric cancer. Eur J Cancer 2004 Oct;40(15):2260-8.
63. Chang VT, Hwang SS, Feuerman M. Validation of the Edmonton Symptom Assessment Scale. Cancer 2000 May 1;88(9):2164-71.
64. Lyons KD, Bakitas M, Hegel MT, Hanscom B, Hull J, Ahles TA. Reliability and Validity of the Functional Assessment of Chronic Illness Therapy-Palliative Care (FACIT-Pal) Scale. J Pain Symptom Manage 2008 May 24.
65. McMillan SC, Weitzner M. Quality of life in cancer patients: use of a revised Hospice Index. Cancer Pract 1998 Sep;6(5):282-8.

66. McMillan SC, Dunbar SB, Zhang W. Validation of the Hospice Quality-of-Life Index and the Constipation Assessment Scale in end-stage cardiac disease patients in hospice care. Journal of Hospice & Palliative Nursing (J HOSP PALLIAT NURS) 10(2): 106-117. 2008.
67. Dobratz MC. The life closure scale: additional psychometric testing of a tool to measure psychological adaptation in death and dying. Res Nurs Health 2004 Feb;27(1):52-62.
68. Salmon P, Manzi F, Valori RM. Measuring the meaning of life for patients with incurable cancer: the life evaluation questionnaire (LEQ). Eur J Cancer 1996 May;32A(5):755-60.
69. Sterkenberg CA, King B, Woodward CA. A reliability and validity study of the McMaster Quality of Life Scale (MQLS) for a palliative population. J Palliative Care 1996;12(1):18-25.
70. Cohen SR, Mount BM, Bruera E, Provost M, Rowe J, Tong K. Validity of the McGill Quality of Life Questionnaire in the palliative care setting: a multi-centre Canadian study demonstrating the importance of the existential domain. Palliat Med 1997 Jan;11(1):3-20.
71. Cohen SR, Mount BM. Living with cancer: 'Good' days and 'Bad' days - What produces them? Can the McGill Quality of Life Questionnaire distinguish between them? Cancer 2000;89(8):1854-65.
72. Lua PL, Salek S, Finlay I, Lloyd-Richards C. The feasibility, reliability and validity of the McGill Quality of Life Questionnaire-Cardiff Short Form (MQOL-CSF) in palliative care population. Qual Life Res 2005 Sep;14(7):1669-81.
73. McCanse RP. The McCanse Readiness for Death Instrument (MRDI): a reliable and valid measure for hospice care. Hosp J 1995;10(1):15-26.
74. Sherman DW, Ye XY, Beyer MC, Parkas V, Calabrese M, Gatto M. Symptom assessment of patients with advanced cancer and AIDS and their family caregivers: the results of a quality-of-life pilot study. Am J Hosp Palliat Care 2007 Oct;24(5):350-65.
75. Lobchuk MM. The memorial symptom assessment scale: modified for use in understanding family caregivers' perceptions of cancer patients' symptom experiences. J Pain Symptom Manage 2003 Jul;26(1):644-54.
76. Chang VT, Hwang SS, Kasimis B, Thaler HT. Shorter symptom assessment instruments: the Condensed Memorial Symptom Assessment Scale (CMSAS). Cancer Invest 2004;22(4):526-36.
77. Hickman SE, Tilden VP, Tolle SW. Family reports of dying patients' distress: the adaptation of a research tool to assess global symptom distress in the last week of life. J Pain Symptom Manage 2001 Jul;22(1):565-74.
78. Byock IR, Merriman MP. Measuring quality of life for patients with terminal illness: the Missoula-VITAS quality of life index. Palliat Med 1998 Jul;12(4):231-44.
79. Schwartz CE, Merriman MP, Reed G, Byock I. Evaluation of the Missoula-VITAS Quality of Life Index--revised: research tool or clinical tool? J Palliat Med 2005 Feb;8(1):121-35.
80. Rainbird KJ, Perkins JJ, Sanson-Fisher RW. The Needs Assessment for Advanced Cancer Patients (NA-ACP): a measure of the perceived needs of patients with advanced, incurable cancer. a study of validity, reliability and acceptability. Psychooncology 2005 Apr;14(4):297-306.

81. Vernooij-Dassen MJ, Osse BH, Schade E, Grol RP. Patient autonomy problems in palliative care: systematic development and evaluation of a questionnaire. J Pain Symptom Manage 2005 Sep;30(3):264-70.
82. Chochinov HM, Hassard T, McClement S, Hack T, Kristjanson LJ, Harlos M, et al. The Patient Dignity Inventory: A Novel Way of Measuring Dignity Related Distress in Palliative Care. J Pain Symptom Manage 2008 Jun 23.
83. Osse BH, Vernooij MJ, Schade E, Grol RP. Towards a new clinical tool for needs assessment in the palliative care of cancer patients: the PNPC instrument. J Pain Symptom Manage 2004 Oct;28(4):329-41.
84. Osse BH, Vernooij-Dassen MJ, Schade E, Grol RP. A practical instrument to explore patients' needs in palliative care: the Problems and Needs in Palliative Care questionnaire short version. Palliat Med 2007 Jul;21(5):391-9.
85. Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the Palliative Care Outcome Scale. Quality in Health Care 1999 Dec;8(4):219-27.
86. Curtis JR, Patrick DL, Engelberg RA, Norris K, Asp C, Byock I. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. J Pain Symptom Manage 2002 Jul;24(1):17-31.
87. Steinhauser KE, Clipp EC, Bosworth HB, McNeilly M, Christakis NA, Voils CI, et al. Measuring quality of life at the end of life: validation of the QUAL-E. Palliat Support Care 2004 Mar;2(1):3-14.
88. Hermann C. Development and testing of the spiritual needs inventory for patients near the end of life. Oncol Nurs Forum 2006 Jul;33(4):737-44.

Appendix 1

Search Strategy

#1 (Palliative Care OR palliative OR Terminal Care OR terminal OR end of life OR limited life OR Hospice Care OR After-Hours Care)

 # 2 (Quality of Life OR quality of life) OR (Religion and Psychology OR spiritual*)

#1 AND #2 → #3

#4 (addresses OR biography OR case reports OR comment OR directory OR editorial OR festschrift OR interview OR lectures OR legal cases OR legislation OR letter OR news OR newspaper article OR patient education handout OR popular works OR congresses OR consensus development conference OR consensus development conference, nih OR practice guideline) NOT (animals NOT humans)

#5 (Clinical Audit OR audit OR outcome assessment (health care) OR instrumentation OR Validation Studies OR reproducibility of results OR reproducib* OR psychometrics OR psychometr* OR clinimetr* OR clinometr* OR item selection OR item reduction OR observer variation OR observer variation OR discriminant analysis OR reliab* OR valid* OR coefficient OR internal consistency OR (cronbach* AND (alpha OR alphas)) OR item correlation OR item correlations OR item selection OR item selections OR item reduction OR item reductions OR agreement OR precision OR imprecision OR precise values OR test-retest OR (test AND retest) OR (reliab* AND (test OR retest)) OR stability OR interrater OR inter-rater OR intrarater OR intra-rater OR intertester OR inter-tester OR intratester OR intra-tester OR interobeserver OR inter-observer OR intraobserver OR intra-observer OR intertechnician OR inter-technician OR intratechnician OR intra-technician OR interexaminer OR inter-examiner OR intraexaminer OR intra-examiner OR interassay OR inter-assay OR intraassay OR intra-assay OR interindividual OR inter-individual OR intraindividual OR intra-individual OR interparticipant OR inter-participant OR intraparticipant OR intra-participant OR kappa OR kappa's OR kappas OR coefficient of variation OR repeatab* OR ((replicab* OR repeated) AND (measure OR measures OR findings OR result OR results OR test OR tests)) OR generaliza* OR generalisa* OR concordance OR (intraclass AND correlation*) OR discriminative OR known group OR factor analysis OR factor analyses OR factor structure OR factor structures OR dimensionality OR subscale* OR multitrait scaling analysis OR multitrait scaling analyses OR item discriminant OR interscale correlation OR interscale correlations OR ((error OR errors) AND (measure* OR correlat* OR evaluat* OR accuracy OR accurate OR precision OR mean)) OR individual variability OR interval variability OR rate variability OR variability analysis OR (uncertainty AND (measurement OR measuring)) OR standard error of measurement OR sensitiv* OR responsive* OR (limit AND detection) OR minimal detectable concentration OR interpretab* OR (small* AND (real OR detectable) AND (change OR difference)) OR meaningful change OR minimal important change OR minimal important difference OR minimally important change OR minimally important difference OR minimal detectable change OR minimal detectable difference OR minimally detectable change OR minimally detectable difference OR minimal real change OR minimal real difference OR minimally real change OR minimally real difference OR ceiling effect OR floor effect OR Item response model OR IRT OR Rasch OR Differential item functioning OR DIF OR computer adaptive testing OR item bank OR cross-cultural equivalence)

(#3 NOT #4) AND #5

Appendix 2

Quality Criteria for Measurement Properties

Property	Definition	Quality criteria [a, b]
Content validity	The extent to which the domain of interest is represented by the items in the questionnaire	+ A clear description is provided of the measurement aim, the target population, the concepts that are being measured, and the item selection AND target population and (investigators OR experts) were involved in item selection AND a full copy of the instrument should be available; ? A clear description of abovementioned aspects is lacking OR only target population involved OR doubtful design or method OR a full copy of the instrument is lacking; - No target population involvement; 0 No information found on target population involvement.
Construct validity	The extent to which scores on a particular instrument correspond to other measures in a manner that is consistent with theoretical expectations concerning the constructs that are being measured	+ Specific hypotheses were formulated AND at least 75% of the results are in accordance with these hypotheses; ? Doubtful design or method (e.g., no hypotheses); - Less than 75% of hypotheses were confirmed, despite adequate design and methods; 0 No information found on construct validity.
Internal consistency	The extent to which items in a (sub)scale are intercorrelated, thus measuring the same construct	+ Factor analyses performed on adequate sample size (7 * # items AND $\geq$ 100) AND Cronbach's alpha(s) calculated per dimension AND Cronbach's alpha(s) between 0.70 and 0.95 ? No factor analysis OR doubtful design[1]; - Cronbach's alpha(s) < 0.70 or > 0.95, despite adequate design and method [2] 0 No information found on internal consistency.
Reliability	The extent to which the instrument is able to distinguish patients from each other, despite measurement error (relative measurement error)	+ ICC or weighted Kappa $\geq$ 0.70 AND time interval at least 1 week [3] ? Doubtful design or method (e.g., time interval not mentioned) - ICC or weighted Kappa < 0.70, despite adequate design and method; 0 No information found on reliability.
Absolute measurement error	The absolute difference between two repeated measures	+ SEM OR MIC < SDC or MIC outside the LOA OR convincing arguments that the measurement error is acceptable; ? Doubtful design of method (OR SEM or MIC not defined AND no convincing arguments that the measurement error is acceptable); - SDC or SDC $\geq$ MIC or MIC equals or inside LOA OR RR $\leq$ 1.96 OR AUC < 0.70, despite adequate design and methods; 0 No information on absolute measurement error.
Responsiveness	The capacity of an instrument to detect clinically important changes over time	+ Specific hypotheses were formulated AND at least 75% of the results are in accordance with these hypotheses AND at least 2 measurements are available AND the time interval is described OR SDC or SDC < MIC or MIC outside the LOA OR RR > 1.96 OR AUC $\geq$ 0.70; ? Doubtful design or method (e.g., no hypotheses); - Less than 75% of hypotheses were confirmed, despite adequate design and methods OR SDC or SDC $\geq$ MIC or MIC equals or inside LOA OR RR $\leq$ 1.96 OR AUC < 0.70, despite adequate design and methods; 0 No information on responsiveness.
Interpretability	The degree to which (change) scores can be interpreted	+ Mean and SD scores presented of at least four relevant subgroups of patients and MIC defined and no floor/ceiling effects were present; ? Doubtful design of method OR less than four subgroups OR no MIC defined OR floor/ceiling effects were present 0 No information found on interpretability.

ICC = intraclass correlation SEM = standard error of measurement; MIC = minimal important change; SDC = smallest detectable change; LOA = limits of agreement; AUC = area under the curve; RR = responsiveness ratio

[a] + = positive rating; ? = indeterminate rating; - = negative rating; 0 = no information available.

b Doubtful design or method = lacking of a clear description of the design or methods or the study, sample size smaller than 50 subjects (should be at least 50 in every (subgroup) analysis), or any important methodological weakness in the design or execution of the study.

[1] 75% of Cronbach's alphas between 0.70 and 0.90 AND no Cronbach's alpha < 0.50

[2] < 75% of Cronbach's alphas between 0.70 and 0.90 OR Cronbach's alpha < 0.50

[3] time interval at least 1 week OR less than 1 week when the questionnaire contains 30 items OR less than 1 week when convincing arguments were given that the time interval was appropriate

Appendix 3

Full Names of the Questionnaires Included

BHI	Brief Hospice Inventory	Guo H et al. (2001)
CAMPAS-R	Cambridge Palliative Audit Schedule	Ewing G et al. (2004)
DS	Demoralization Scale	Kissane DW et al. (2004)
EFAT	Edmonton Functional Assessment Tool	Kaasa T et al. (1997; 2001)
	Emanuel and Emanuel Medical Directive	Schwartz CE et al. (2004)
EORTC QLQ-OES18	European Organisation for Research and Treatment of Cancerr Quality of Life Questionnaire – Oesophageal cancer module	Blazeby JM et al. (2003)
EORTC QLQ-STO22	European Organisation for Research and Treatment of Cancerr Quality of Life Questionnaire – Gastric cancer module	Blazeby JM et al. (2004)
ESAS	Edmonton Symptom Assessment Scale	Chang VT et al. (2000)
FACIT-Pal	Functional Assessment of Chronic Illness Therapy-Palliative subscale	Lyons KD et al. (2008)
HQLI	Hospice Quality of Life Index	McMillan et al. (1998; 2008)
LCS	Life Closure Scale	Dobratz MC et al. (2004)
LEQ	Life Evaluation Questionnaire	Salmon P et al. (1996)
MQLS	McMaster Quality of Life Scale	Sterkenburg CA et al. (1996)
MQOL	McGill Quality of Life Questionnaire	Cohen SR et al. (1997; 2000)
MQOL-CSF	McGill Quality of Life Questionnaire-Cardiff Short Form	Lua PL et al. (2005)
MRDI	McCanse Readiness for Death Instrument	McCanse RP et al. (1995)
MSAS	Memorial Symptom Assessment Scale	Sherman DW et al. (2007); Lobchuk MM et al. (2003)
CMSAS	Condensed Memorial Symptom Assessment Scale	Chang VT et al. (2004)
MSAS-GDI	Memorial Symptom Assessment Scale-Global Distress Index	Hickman SE et al. (2001)
MVQOLI	Missoula-VITAS Quality of Life Index	Byock IR et al. (1998); Schwartz CE et al. (2005)
NA-ACP	Needs Assessment for Advanced Cancer Patients	Rainbird KJ et al. (2005)
PAQ	Patient Autonomy Questionnaire	Vernooij-Dassen MJ et al. (2005)
PDI	Patient Dignity Inventory	Chochinov HM et al. (2008)
PNPC	Problems and Needs in Palliative Care questionnaire	Osse BH et al. (2004)
PNPC-sv	Problems and Needs in Palliative Care questionnaire-short version	Osse BHI et al. (2007)
POS	Palliative care Outcome Scale	Hearn J et al. (1999)
QODD	Quality of Dying and Death questionnaire	Curtis JR et al. (2002)
QUAL-E	Quality of life at the end of life	Steinhauser KE et al. (2004)
SNI	Spiritual Needs Inventory	Hermann CP et al. (2006)

Part III

Measuring dignity at the end of life

Chapter 5

Analysis of the construct of dignity and the content validity of the patient dignity inventory

Gwenda Albers, H Roeline W Pasman, Mette L Rurup, Henrica CW de Vet, Bregje D Onwuteaka-Philipsen

Published in Health and Quality of Life Outcomes 2011,9:45

Abstract

Backgound
Maintaining dignity, the quality of being worthy of esteem or respect, is considered as a goal of palliative care. The aim of this study was to analyse the construct of personal dignity and to assess the content validity of the Patient Dignity Inventory (PDI) in people with an advance directive in the Netherlands.

Methods
Data were collected within the framework of an advance directives cohort study. This cohort study is aiming to get a better insight into how decisions are made at the end of life with regard to advance directives in the Netherlands. One half of the cohort (n=2404) received an open-ended question concerning factors relevant to dignity. Content labels were assigned to issues mentioned in the responses to the open-ended question. The other half of the cohort (n=2537) received a written questionnaire including the PDI. The relevance and comprehensiveness of the PDI items were assessed with the COSMIN checklist ('COnsensusbased Standards for the selection of health status Measurement INstruments').

Results
The majority of the PDI items were found to be relevant for the construct to be measured, the study population, and the purpose of the study but the items were not completely comprehensive. The responses to the open-ended question indicated that communication and care-related aspects were also important for dignity.

Conclusions
This study demonstrated that the PDI items were relevant for people with an advance directive in the Netherlands. The comprehensiveness of the items can be improved by including items concerning communication and care.

Introduction

Dignity is a topic which often arises in discussions about care for dying patients. Since the concept of dignity is not clearly defined in palliative care, the term dignity is used in many different ways, and easily invokes confusion. Although, several authors have argued that dignity should be considered as a central principle in palliative care,[1-3] and that conserving dignity can be considered as a goal of the care that is provided.[4-7]

Dignity can be defined as the quality of being worthy of esteem or respect. A distinction can be made between two types of dignity: basic dignity and personal dignity. Basic dignity is the inherent dignity of every human being, which nothing can take away, and personal dignity refers to a personal sense of worth, associated with personal goals and social circumstances. It is related to a persons' self-esteem and perceptions of being respected by others, and consequently it can be taken away or enhanced.[8-9] The current study focused on personal dignity at the end of life.

Preserving dignity is frequently mentioned by patients when considering the end of life. Consequently, concern about loss of dignity is one of the most common reasons why people formulate an advance directive in the Netherlands.[10] In addition, loss of dignity is one of the most frequently mentioned reasons for requesting euthanasia or physician-assisted suicide.[11, 12] The law in Oregon concerning physician-assisted suicide is even called 'the Oregon Death with Dignity Act'.[11]Hence, considering end-of-life care from patient perspective the concept of dignity can contribute to palliative care research.

An adequate measurement instrument to identify aspects that cause distress at the end of life will provide insight into the issues that are relevant and important for a person's sense of dignity. Understanding the causes of dignity-related distress could help to improve palliative care and research in palliative care.

Based on a qualitative study focusing on how dying cancer patients in Canada understand and define dignity, Chochinov et al. developed an empirical model of dignity to understand how patients face an advancing terminal illness.[13] Items were developed from the themes and sub-themes in the model, and terminally ill cancer patients were asked how much they thought that these items could influence their sense of dignity. In this way the dignity model was validated, and a first draft of the Patient Dignity Inventory (PDI) was developed.[14] This 22-item PDI prototype was later revised and became the 25-item PDI, a measurement instrument which can be used by clinicians to detect end-of-life dignity-related distress.[15]

In Canada the PDI has been found to be a valid and adequate instrument for use in patients with terminal cancer, but it is unclear if and to what extent the PDI items are relevant for other groups of patients or for patients in other countries. Some people, when they get older, or they or their loved ones have been confronted with disease, become concerned about their dignity, think about their wishes with regard to end-of-life care, and formulate an advance directive.

Advance directives are documents in which one can state one's preferences concerning end-of-life care, aimed at making someone's wishes known in situations where he/she is not able to do so in another manner. In the Netherlands, the most common standard advance directives, the advance euthanasia directive, the refusal of treatment statement and the durable power of attorney (appointment of a health care representative) are provided by the Right to Die-NL, and the wish to live statement (stating the wish to receive adequate care directed at quality of life, and explicitly refusing euthanasia), is provided by the Dutch Patient Association.

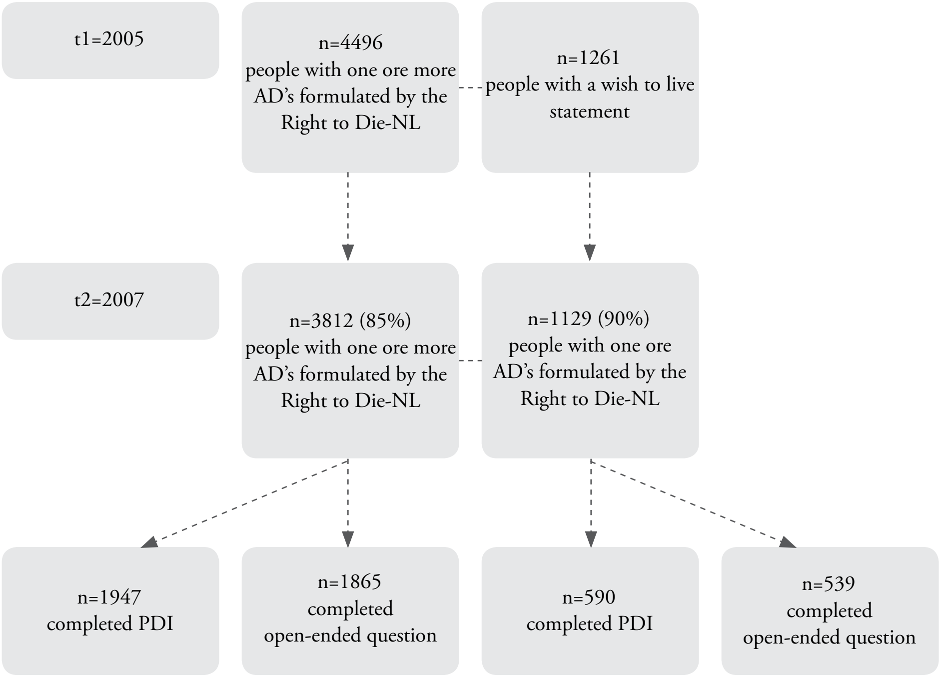
Given that people with an advance directive have thought about and realise the importance of end-of-life issues, it is of great interest to study their ideas about dignity, because these can be very useful for health care providers in organising advance care-planning. Therefore, we performed a content analysis of the construct of dignity for a broader population than cancer patients, to investigate which items influence personal dignity for people with an advance directive in the Netherlands. Furthermore, we investigated the content validity of the PDI by assessing the relevance and the comprehensiveness of the PDI items with the COSMIN checklist (COnsensus-based Standards for the selection of health status Measurement INstruments).[16,17]

Methods

Design and study population

The data for this study were collected within the framework of the Advance Directives Cohort Study.[18] The study was approved by the Medical Ethics Review Committee of the VU University Medical Center. The Advance Directives Cohort Study is a major ongoing longitudinal study aiming to get insight into how advance directives are involved in end-of-life decisions in the Netherlands. This cohort study started in 2005, and follow-up measurements are performed once every one and a half years. The design of the Advance Directives Cohort is described in detail by Van Wijmen et al.[18] The data used in the present study were collected during the second cycle of data collection. A written questionnaire with structured questions was sent to the cohort of participants with one or more of the most common standard advance directives in the Netherlands provided by the Right to Die-NL and the Dutch Patient Association. During the first data-collection cycle the cohort consisted of 4,496 people who had one or more advance directives formulated by the Right to Die-NL, and 1,261 people who had a wish to live statement. The response rate in the second data-collection cycle was 85% respectively 90% for the Right to Die-NL members and the members of the Dutch Patients Association (see Figure 1).

Figure 1 Flow Chart of Recruitment and Response Rates



The present study is based on data which were collected in the Spring of 2007. We randomly split the cohort into two by alternately placing cases in one of two subsamples; one half received a questionnaire which included an open-ended question concerning important factors for personal dignity, and the other half received the PDI. Accordingly, there were four groups: 1) people with one or more advance directives from the Right to Die-NL who received the open-ended question, 2) people with one or more advance directives from the Right to Die-NL who received the PDI, and 3) people with a wish to live statement who received the open-ended question, and 4) people with a wish to live statement who received the PDI. A total of 3,812 people with one or more advance directives (95% had an advance euthanasia directive, 65% had the refusal of treatment statement, and 63% had the durable power of attorney) and 1,129 members of the Dutch Patient Association completed the questionnaire in the second data-collection cycle.

Measurement instrument

All respondents were asked some questions about demographic characteristics and how they rated their health status (very good; good; less than good).

As described above, one randomly selected half of the cohort received an open-ended question, which was introduced with the following text: 'The term dignity is often used when talking about the last phase of life. However, little is known about what exactly influences a person's sense of dignity'. These respondents were asked two questions: 'Please describe how you would define dignity", and 'what issues do you think that would influence your sense of dignity during the last phase of their life?'.

The other randomly selected half of the cohort received the PDI, in which they were asked to rate the extent to which they though the items could influence their sense of dignity during the last phase of life, on a 5-point scale (1=not at all; 2=slightly; 3=moderately; 4=a lot; 5=very much). The PDI was introduced with a text similar to that introducing the open-ended question. In order to assess the comprehensiveness of the PDI items, the respondents were also asked whether they thought that there were any items missing in the PDI which could influence their sense of dignity during the last phase of life.

This study is based on the PDI prototype, a measurement instrument that can be used to assess various sources of dignity-related distress among cancer patients nearing the end of life.[14] This first version of the PDI consists of 22 items, divided into four domains (i.e. psychological, physical, social and existential) that influence the sense of dignity of terminally ill cancer patients. The items were translated into Dutch by means of forward and backward translation. The PDI items were independently translated from English to Dutch by two researchers. Two other researchers with no knowledge of the PDI of whom one native speaker did the backward translation. The two backward translations were compared and only small differences were found and resolved by consensus. Subsequently, the Dutch version was tested in a pilot study consisting of people with an advance directive. The pilot showed that the item "Thinking how life might end" was not considered as influential to sense of dignity at the end of life. This might have been expected since the majority of the study population was in good health. Therefore, we decided to exclude this item of the original PDI prototype.

Analyses

We analysed the responses to the open-ended question to address the first aim of this study, i.e. the content analyses of the construct of dignity. We first organised the data obtained from the responses to the open-ended question. Sub-themes referring to any aspect of dignity were assigned to all of these responses and content labels were assigned to the sub-themes. We started off by structuring our labels according to the four domains (physical, psychological, social, existential) and the PDI-items distinguished by Chochinov et al. These domains were used as layers for the four columns within a scheme in which the content labels were placed. Two researchers (familiar with the PDI) independently read and applied content labels to 400 responses open-end responses. These labels were compared, and any disagreements between the researchers were discussed and resolved. This process continued until there was complete consensus regarding the labelling, and no additional content labels were assigned or added to the scheme.

The COSMIN checklist was used to address the second aim of this study, which was to analyse the content validity of the PDI. According to the COSMIN taxonomy of measurement properties, which is based on an international Delphi study, content validity is defined as: the degree to which the content of a measurement instrument is an adequate reflection of the construct to be measured.[19] As described above, in this study the construct of dignity was defined by the issues that were mentioned as important for dignity in the responses to the open-ended question. According to the COSMIN checklist, 5 questions should be answered to assess content validity (Table 1).

Table 1 Content Validity Box from the COSMIN Checklist

Box D. Content validity (including face validity)				
	General requirements	**yes**	**no**	**?**
1	Was assessed if all items refer to relevant aspects of the construct to be measured?	☐	☐	☐
2	Was assessed if all items are relevant for the study population? Considering e.g. age, gender, disease characteristics, country, setting	☐	☐	☐
3	Was assessed if all items are relevant for the purpose of the application of the measurement instrument? i.e. (1) discriminative (distinguish between groups at one point in time), (2) evaluative (assess change over time), and/or (3) predictive (predict future values)	☐	☐	☐
4	Was assessed if all items together comprehensively reflect the construct to be measured in terms of (1) content coverage and description of domains, and (2) the theoretical foundation?	☐	☐	☐
5	Were there any important flaws in the design or methods of the study?	☐	☐	

First, we assessed whether all items of the PDI were represented in the responses to the open-ended question (COSMIN requirement 1).

Secondly, we assessed whether the focus and detail of the content of the PDI match the target population. In other words, we assessed whether each PDI item was relevant for the study population by calculating the percentage per item of people who scored 4 or 5 on the 5 point scale. These percentages indicate how many people considered that the items would influence dignity at the end of their life (COSMIN requirement 2). In this way, the study population judged the relevance of the items. In addition, we checked the number of missing observations given that many missing observations on an item can be an indication that the item is not relevant for the population.

The third COSMIN requirement determines whether all items are relevant for the purpose of the application of the instrument. This items is not applicable since this study aims to examine whether the PDI items are relevant for a population different from the population in which the instrument was originally developed. In this study the instrument has not been subjected to a discriminative, evaluative or predictive application.

In addition, we assessed whether the PDI items comprehensively reflect the construct of dignity. Hence, we assessed the extent to which issues mentioned as important for a person's sense of dignity in the responses to the open-ended question were represented in the PDI items (COSMIN requirement 4).

The last COSMIN item (COSMIN requirement 5) determines whether there are any important flaws in the design or methods of the study. This item is only applicable when evaluating a study, and not when performing a study to assess the content validity of health measurement instruments.

Results

Response rates

The response rate in the people who received the questionnaire including the PDI varied per item, from 88% to 92% among people with an advance directive from the Right to die-NL and from 80% to 84% in people with a wish to live statement. The majority of the people who received the open-ended question could describe how they understand dignity and could also describe some issues which they thought would influence their sense of dignity during the last phase of their life. The response rate was 91% and 82%, respectively, in the people with an advance directive from the Right to die-NL and the people with a wish to live statement who received the open-ended question.

Characteristics of the respondents

Table 2 presents the characteristics of the respondents. More than half of all the respondents were female, and the mean age in all groups was between 60 and 70 years of age. Almost all people with a wish to live statement had religious beliefs, compared to 36% of the people with an advance directive formulated by the Right to die-NL. The study population consisted of people with different ratings for health status, a majority of whom assessed their health status as good.

Table 2 Characteristics of the People with one or more Advance Directives from the Right to Die-NL and People with a Wish to Live Statement

Characteristics	**People with an advance directive from the Right to die-NL**		**People having a wish to live statement**	
	PDI **n=1947**	**Open-ended question** **n=1865**	**PDI** **n=590**	**Open-ended questio** **n=539**
Kind of advance directive				
- Advance euthanasia directive	95	94		
- Refusal of treatment document	65	64		
- Durable power of attorney	63	63		
Sex, female %	61	68	60	59
Age mean (SD) [range]	69 (12) [26-98]	70 (12) [25-100]	61 (17) [17-92]	62 (17) [19-92]
Marital status %				
Single/divorced/widowed	41	42	29	28
Married or with partner	59	58	71	72
Level of education[1] %				
Low	5	6	13	16
Intermediate	55	56	66	60
High	40	38	21	24
Religious beliefs %	35	37	99	99
Self perceived health status				
Very good	19	20	22	19
Good	59	58	59	61
Less than good	22	23	16	19

[1] Low: Lower vocational education; lower secondary general education; primary school. Intermediate: Intermediate vocational or higher secondary general education. High: Higher vocational education; university.

Construct of dignity

All issues mentioned in the responses to the open-ended question were used to define the construct of dignity in this study. The Additional file 1, Table S1 contains a list of issues which were considered to influence dignity by people with an advance directive, and which consequently define the content of the construct of dignity. Issues most frequently mentioned were: independence, incontinence, pain, mental clarity, dementia, the ability to communicate and adequate care. During the coding process it became apparent that care-related aspects were not covered by any of the domains, but were thought to influence dignity, so we added care as a sub-theme.

Relevance of the PDI items

Analysing the content validity of the PDI, we assessed the relevance of the PDI items for (1) the construct to be measured, (2) the study population, and (3) the purpose of the study.

Firstly, the majority of the PDI items were relevant for the construct to be measured, because they were represented in the responses to the open-ended question. However, some PDI items, i.e. ‘changes in physical appearance’, ‘not being able to carry out important roles’, ‘not feeling you made a meaning or lasting contribution’, ‘not being able to mentally fight’, ‘not being able to accept things the way they are’ and ‘uncertainty regarding illness’ were not or only (very) seldom reflected in the responses to the open-ended question (COSMIN requirement 1). In accordance, these PDI items were the least frequently indicated as influential for dignity by the respondents who completed the PDI (see Table 3).

Secondly, Table 3 shows the mean and SD together with the percentages of (strong) agreement, indicating that each PDI item is considered to influence dignity at the end of life (COSMIN requirement 2). However, one of the items, ‘changes in physical appearance’ was only considered to influence sense of dignity by a small number of respondents in both groups, so it might be considered to be less relevant for the present study population.

Table 3 PDI Items considered to influence sense of Dignity at the End of Life by People with one or more Advance Directives from the Right to Die-NL and People with a Wish to Live Statement

	Range of distribution Mean (SD)	**People with an advance directive from the Right to die-NL n=1947 %***	**People with a wish to live statement n=590* %***
Physical aspects			
Not being able to independently manage bodily functions	3.7 (1.3)	73	41
Not being able to carry out tasks of daily living	3.4 (1.3)	58	28
Not being able to continue with usual routines	3.1 (1.2)	45	27
Experiencing distressing symptoms	3.1 (1.1)	37	31
Not being able to carry out important roles	2.7 (1.2)	29	19
Changes in physical appearance	2.2 (1.1)	12	18
Psychological aspects			
Not being able to think clearly	3.8 (1.2)	73	53
Not being able to mentally fight	3.6 (1.2)	61	38
Feeling depressed or anxious	3.3 (1.2)	51	42
Not being able to accept things the way they are	3.2 (1.3)	45	36
Social aspects			
Feeling a burden to others	3.8 (1.3)	74	50
Not being treated with respect or understanding	3.4 (1.3)	52	57
Feeling your privacy has been reduced	3.2 (1.2)	49	38
Not feeling supported by your community	3.2 (1.3)	43	48
Existential aspects			
Feeling you do not have control over your life	3.6 (1.3)	67	38
No longer feeling like who you were	3.5 (1.3)	59	45
Feeling life no longer has meaning or purpose	3.3 (1.4)	58	33
Not feeling worthwhile or valued	3.2 (1.3)	43	44
Not having a meaningful spiritual life	2.9 (1.4)	33	41
Uncertainty regarding illness	2.9 (1.2)	31	33
Not feeling you made a meaning or lasting contribution	2.6 (1.2)	23	21

[*] Percentage that agree or strongly agree (scored a 4 or 5 on a 5-point scale) that the aspect influence the sense of dignity during the last phase of life

∞ 21 items are included because the items “Thinking how life might end” of the original PDI prototype was excluded from the current study as a result of a pilot study

Comprehensiveness of the PDI items

Finally, a comparison of the results from the PDI and the responses to the open-ended question (COSMIN requirement 4) showed that most issues described in the responses were covered by the PDI items.

Issues not represented in the PDI were aspects related to care and the ability to communicate. Table 4 shows that communication as a way of indicating what a person wants, and communication as a social activity, are both thought to be issues that are relevant for dignity at the end of life. In addition, Table 5 shows a variety of care-related issues which are considered to be important for dignity. The people who completed the PDI indicated that communication and care-related aspects were issues which were missing in the PDI, as well as the following issues: independence, pain, incontinence, dementia, being treated with respect, and the ability to wash, eat and drink independently, and to go to the toilet without help.

Table 4 Content Labels applied to Responses to the Open-ended Question concerning Social Aspects

SOCIAL
Being able to communicate (in general)
Communication as a means of indicating what a person wants
Communication as a social activity

Table 5 Content Labels applied to Responses to the Open-ended Question concerning Care-related Issues

CARE
Environmental aspects of care
Being cared for in a quiet/safe place
Being cared for at home/not in an institution
Not being cared for by strangers/many different people
Being cared for in a hospice
Desired treatment goals
No unnecessary prolongation of life/being allowed to ‘let go’
(No) hastened death/euthanasia
Adequate pain (and symptom) management/relief of suffering
Relief suffering
Palliative care
Care characteristics
Adequate care/tailored care
Warm loving care
Spiritual support

The responses to the open-ended question described the issues in more detail, or in a different way, compared to the PDI items. For example, the PDI item 'not being able to independently manage bodily functions' is represented in the following issues mentioned in the responses to the open-end question, but more specifically described as: incontinence, and being able to wash, eat and drink independently (see Table 6).

Table 6 Content Labels applied to Responses to the Open-ended Question concerning Physical Issues

PHYSICAL
Independence
Not being able to independently manage bodily functions (PDI item)
Not being able to carry out tasks of daily living (PDI item)
Incontinence
Not being able to wash and bath independently
Not being able to eat/drink independently
Immobile/bedridden

Discussion

With the COSMIN checklist we assessed the content validity of the PDI in people with an advance directive in the Netherlands. All of the PDI items, apart from the item "Thinking how life might end", were thought to be relevant to sense of dignity at the end of life by people with an advance directive formulated by the Right to die-NL, and by people with a wish to live statement. However, the PDI items did not comprehensively reflect the construct of dignity, because the PDI lacks items about communication and care characteristics. In the responses to the open-ended question these were mentioned as important issues that influence dignity and these were also indicated as missing items in the PDI.

PDI items versus responses to open-ended question

The issues that were most frequently indicated as important for sense of dignity, such as the ability to manage bodily functions, the ability to think clearly and feeling a burden to others, in the responses to the open-ended question also received the highest scores in the PDI, and vice versa PDI items that were the least frequently mentioned as influential for dignity, such as changes in physical appearance were also the issues that were the least frequently mentioned in the responses to the open-ended question, although the latter gave more detailed information.

The respondents who completed the PDI indicated that they missed items in the PDI, for instance about the ability to wash, eat and drink independently, and to go to the toilet without help. Nevertheless, these issues are basically represented by the PDI item 'not being able to independently manage bodily functions'. This indicates that the PDI items are quite abstract, and are not clear for all respondents. People possibly prefer more specific phrasing such as, 'not being able to independently get to the toilet'.

The responses to the open-ended question show that being able to communicate and care-related aspects are relevant for a person's sense of dignity, whereas these issues are not included in the PDI. However, communication and various care-related issues were mentioned as missing items in the PDI, demonstrating once more that these are important issues. In Chochinov's model of dignity, care tenor is recognised as a sub-theme of the social dignity inventory. It relates to the attitudes other people demonstrate when interacting with a patient.[13] Care tenor is represented by the PDI item concerning being treated with respect. However, this item is very general, and does not specify how the attitudes of health care providers influence a person's dignity. The revised 25-item PDI includes an additional item: 'not feeling supported by my health care providers'. In addition, in a study investigating the dignity-conserving model, it was found that staff had a considerable impact on the sense of dignity of people living in nursing homes.[20] Nevertheless, the present study indicates that care-related aspects, e.g. the location of care also influence dignity. Even though the care related aspects are not covered by the social domain, and required the addition of a separate care domain, and the results of this study demonstrated the importance of care and communication for dignity, it is still debatable whether a separate domain for care is the best option.

Use of PDI in people with an advance directive

The respondents were asked what issues they thought would influence their sense of dignity during the last phase of their life. However, these people were not in the last phase of their life, and we did not know whether they were able to conceive of a situation in which they were terminally ill when responding to this question. Nevertheless, the aim of this study was to determine whether the PDI can be used in people with an advance directive, because thinking in advance about dignity at the end of their life could be helpful in the organisation of advance care-planning for people who are not (terminally) ill. This study population, which consisted of people with an advance directive or a will to live statement, have probably already thought about end-of-life issues. Respondents might have thought more profoundly about end-of-life issues since they have formulated their wishes concerning end-of-life care in an advance directive which enhances the quality of the data. However, the results of this study might not be generalized to other populations since the study population consisted of two extreme groups regarding views on end-of-life care; members of the NVVE having an advance euthanasia directive, refusal of treatment statement and/or durable power of attorney, and members of the NPV, people with strong religious beliefs who declared that he/she wish for proper care, meaning no excessive, medically useless treatments at the end of life but also no actions with the purpose of actively terminating his life. Though, these two groups are very explicit and definite with regard to their views on end-of-life care issues, it is likely that the thoughts and views of the majority of the Dutch general population are covered by the results of this study.

It was noticeable that the results of this study are largely in accordance with the issues which were considered as influential to dignity in studies focusing terminally ill cancer patients by Chochinov et al. Hence, it is very likely that the findings can be generalised to populations in other countries because the explicit and definite views on end-of-life care issues also exists in other countries. For instance, 'not being able to think clearly' was found as highest ranked item in the psychological domain and 'feeling you do not have control over your life' was found as highest ranked item in the existential domain in both Chochinovs and our study.[14] However, the terminally ill cancer patients indicated more often that they (strongly) agreed that the PDI items influenced dignity. This applies, for example, to the item 'changes in physical appearance' that 66% of the terminally ill patients considered to be influential for dignity, compared to 12-18% in the present study. Therefore, it seems that some issues only become important for dignity when people are terminally ill.

Strengths and limitations

An important strength is that this is a large-scale study. Therefore, it was possible to subdivide the cohort into two groups, i.e. the PDI group and the group who received the open-ended question, which was important for adequate assessment of the content validity of the PDI in this study population. We assessed the content validity in a structured way, using the COSMIN checklist as a guideline for designing and reporting on the content validity of the PDI in people with an advance directive in the Netherlands.

A limitation of this study could be that the researchers who labelled the responses to the open-ended question were already familiar with the PDI. Moreover, the present study focused on the 22-item PDI prototype, and not on the final revised 25-item PDI, which was published during the period of data-collection for this study.

Conclusion

In view of the ageing population, and the fact that people live for a longer period of their life in a poor health, understanding concerns about dignity becomes increasingly important. The present large-scale study demonstrates the relevance of the PDI items for people with an advance directive in the Netherlands. We found that, in addition to being valid for use in terminally ill cancer patients, the PDI can also be used in a general population to obtain insight into people's thoughts about what would constitute dignity in the last phase of their life. However, the comprehensiveness of the PDI items can be improved by including items concerning communication and care-related aspects. Additionally, the PDI could be improved by more specific phrasing of the items. Finally, the addition of an open-ended question to the PDI could be helpful, acknowledging the fact that what constitutes dignity is personal, and can be different for every person.

Reference List

1. Brant JM. The art of palliative care: living with hope, dying with dignity. Oncol Nurs Forum 1998 Jul;25(6):995-1004.
2. Coppens M. "Death with dignity". Am J Nurs 1998 Dec;98(12):23.
3. Latimer E. Caring for seriously ill and dying patients: the philosophy and ethics. CMAJ 1991 Apr 1;144(7):859-64.
4. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. J Clin Oncol 2005 Aug 20;23(24):5520-5.
5. Geyman JP. Dying and death of a family member. J Fam Pract 1983 Jul;17(1):125-34.
6. McClement SE, Chochinov HM, Hack TF, Kristjanson LJ, Harlos M. Dignity-conserving care: application of research findings to practice. Int J Palliat Nurs 2004 Apr;10(4):173-9.
7. Turner K, Chye R, Aggarwal G, Philip J, Skeels A, Lickiss JN. Dignity in dying: a preliminary study of patients in the last three days of life. J Palliat Care 1996;12(2):7-13.
8. Pellegrino ED. Some things ought never be done: moral absolutes in clinical ethics. Theor Med Bioeth 2005;26(6):469-86.
9. Pullman D. Human dignity and the ethics and aesthetics of pain and suffering. Theor Med Bioeth 2002;23(1):75-94.
10. Ganzini L, Nelson HD, Schmidt TA, Kraemer DF, Delorit MA, Lee MA. Physicians' experiences with the Oregon Death with Dignity Act. N Engl J Med 2000 Feb 24;342(8):557-63.
11. Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. N Engl J Med 1998 Apr 23;338(17):1193-201.
12. Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. Soc Sci Med 2002 Feb;54(3):433-43.
13. Chochinov HM, Krisjanson LJ, Hack TF, Hassard T, McClement S, Harlos M. Dignity in the terminally ill: revisited. J Palliat Med 2006 Jun;9(3):666-72.
14. Chochinov HM, Hassard T, McClement S, Hack T, Kristjanson LJ, Harlos M, et al. The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care. J Pain Symptom Manage 2008 Dec;36(6):559-71.
15. Mokkink LB, Terwee CB, Knol DL, Stratford PW, Alonso J, Patrick DL, et al. The COSMIN checklist for evaluating the methodological quality of studies on measurement properties: A clarification of its content. BMC Medical Research Methodology . 2010.
16. Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Stratford PW, et al. The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. Quality of Life Research . 2010.
17. Van Wijmen MPS, Rurup ML, Pasman HRW, Onwuteaka-Philipsen BD. Design of the Advance Directives Cohort: a study of end-life decision-making focusing on Advance Directives. BMC Public Health. 2010 Mar 26;10:166.

18. Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Knol DL, et al. International consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported ouctomes: results of the COSMIN study. Journal of Clinical Epidemology 2010.
19. Hankins M. How discriminating are discriminative instruments? Health Qual Life Outcomes 2008;6:36.
20. Hall S, Longhurst S, Higginson I. Living and dying with dignity: a qualitative study of the views of older people in nursing homes. Age Ageing 2009 Jul;38(4):411-6.

Appendix 1. Content Labels applied to the Responses to the Open-ended Question

PHYSICAL	PSYCHOLOGICAL	SOCIAL	EXISTENTIAL
Independence	**Mental clarity *(Not being able to think clearly)***	***Feeling a burden to others***	***Feeling you do not have control over your life***
Not being able to independently manage bodily functions	Dementia	***Feeling your privacy has been reduced***	In 'common' life
Incontinence	(Sub-)comatose	Meddlesome	Unable to make decisions concerning treatment/life and death
	Being a vegetable/dependent on life-support		No right to self-determination
Not being able to wash and bath independently	Disoriented in time/place	***Not being treated with respect or understanding***	***No longer feeling like who you were***
Not being able to eat/drink independently	Not recognising family members/loved ones	No respect for religion	***Not feeling worthwhile or valued***
Not being able to carry out tasks of daily living	Incompetent for decision-making	Not treated with respect	No longer feeling valuable to others
Immobile/bedridden	***Feeling depressed or anxious***	No affectionate warm/loving care	(Loss of) decorum
Changes in physical appearance	Fear of death	Not being taken seriously by the physician	Normal thinking/talking
Emaciated	Concerns about surviving relatives	Not being patronized	Self respect
Hair-loss	***Not being able to accept things the way they are***	Spiritual counselling	**Desired treatment goal**
Senile decay/slovenly	Problems in maintaining normal routine	Respect for life (and death)	No prolongation of life/being allowed to 'let go'
Experiencing distressing symptoms	No (inner) acceptance/not at peace with oneself	Respect for the wishes of the patient/family members	No hastened death/euthanasia
Pain	***Not being able to mentally fight***	***Not feeling supported by your community***	Adequate pain(/symptom) management
Dyspnoea		Regarding (practical) care	Euthanasia
Poor eyesight		Regarding attention/understanding	Relief of suffering
Hearing problems		Loneliness	Palliative care
Limitations in (leisure) activities		Presence of loved ones/Saying good bye to loved ones	***Feeling life no longer has meaning or purpose***
Not being able to carry out important roles		**Ability to communicate**	No longer enjoying anything
Unable to take care of loved ones		As a means to indicate what you want	No prospect of improvement/incurable disease
		As a social activity	Losing interest in people/things around you
Not being able to continue with usual routines			***Not having a meaningful spiritual life***
Hobbies		**Environmental aspects of care**	***Uncertainty regarding illness***
Work		Being cared for in a quite/safe place	***Thinking how life might end***
Not living as you want to live		Being cared for at home/not in an institution	
		Not being cared for by strangers/many different people	**OTHER**
		Being cared for in a hospice	Adequate care/tailored care
			You should not judge dignity yourself (God should do this)

Italic items are PDI items

Chapter 6

Does health status affect perceptions of factors influencing dignity at the end of life?

Gwenda Albers, H Roeline W Pasman, Luc Deliens, Henrica CW de Vet, Bregje D Onwuteaka-Philipsen

Accepted for publication in Journal of Pain and Symptom Management

Abstract

Context
More people survive to old ages, and chronic diseases tend to become more common with age. Ill health and disability can lead to concerns about loss of personal dignity.

Objectives
To investigate whether health status affects the perceptions of factors influencing personal dignity at the end of life, and the relationship between those perceptions and socio-demographic characteristics.

Methods
A subsample (n=2282) of a large advance directives cohort study was used. Three different health status groups (good, moderate and poor) were defined based on the EQ-5D and a question on whether they had an illness. For each health status group we calculated the percentage of respondents who indicated the extent to which the items of the Patient Dignity Inventory would influence their dignity as (very) large. Logistic regression analyses were used to investigate the associations between the perceptions of factors influencing personal dignity and socio-demographics.

Results
The percentage of respondents who indicated the factors as having a (very) large influence on dignity at the end of life were not significantly different for the three health status groups, except for three physical items on symptoms, roles and routines. Those items were significantly more influential on dignity for people with a poor health status. Gender, old age, having a partner and having a belief or religion that is important to one's life were associated with an understanding of factors influential to dignity.

Conclusion
Health status seems only to affect the perceptions on physical factors maintaining dignity at the end of life. This might suggest that the understanding of dignity will not substantially change as health status changes and may support starting advance care planning early.

Introduction

The European population is ageing with increasingly more people who suffer and die from serious chronic diseases such as cancer, cerebrovascular disease, heart disease and dementia.[1] As the average life expectancy has increased in the past decades [2] and chronic diseases tend to become more common with age, people not only live longer, they also live a relatively longer period of life with chronic diseases. An Irish study found that 23% of people over 65 had a disability, and that this percentage rises to 65% for those over 80.[3] These findings are in accordance with the 'expansion of morbidity hypothesis', which states that mortality reductions will produce more years with morbidity and related disability.[4-6]

Ill health and disability can lead to concerns about loss of personal dignity. Loss or decline in dignity due to chronic disease frequently referred to in end of life care. Accordingly, several studies have shown that loss of dignity is closely related to patient's wishes for death.[7-10] In addition, it has been found that a concern about loss of dignity was one of the most common reasons to formulate an advance directive in the Netherlands.[11]

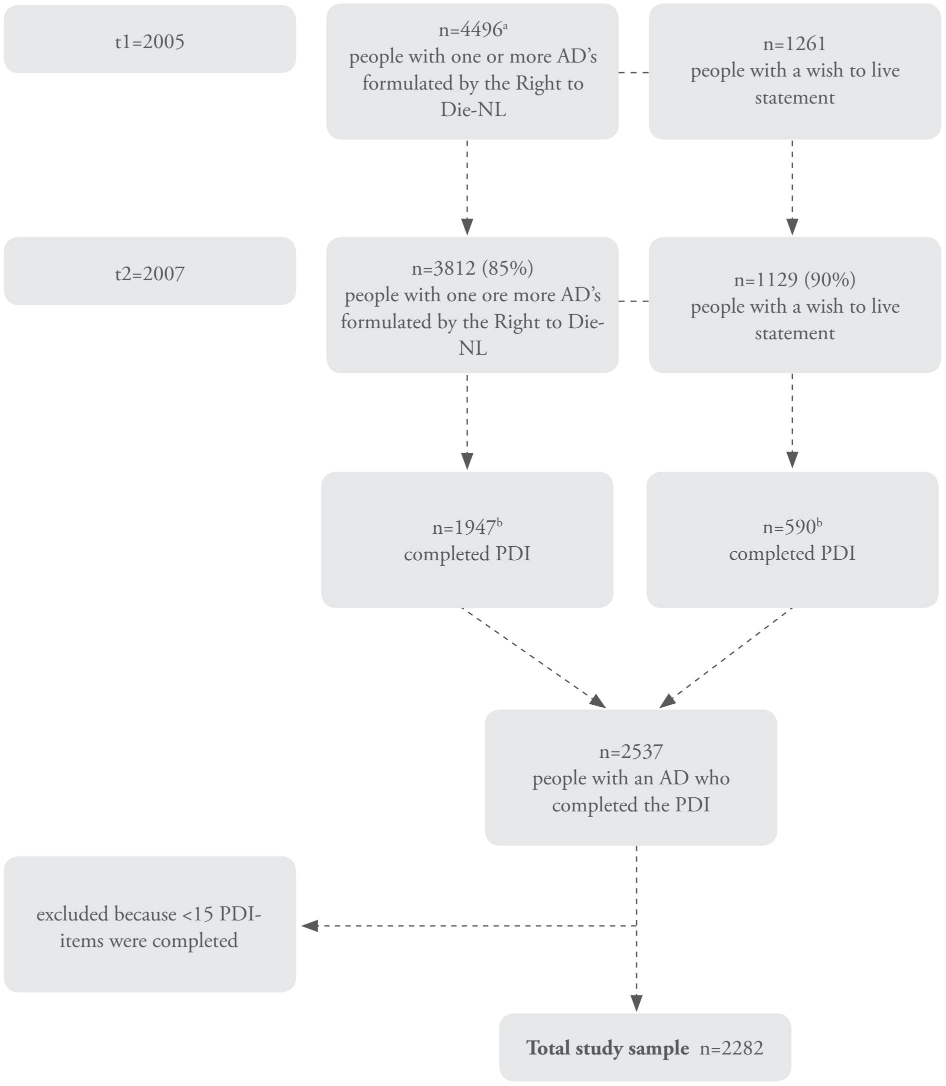
A variety of studies identified factors and themes that may have an impact on patients sense of dignity.[12-17] Chochinov and colleagues demonstrated that the care for terminally ill patients should focus on a broad range of physical, psychological, social, and spiritual/existential issues in order to promote a patient's sense of dignity.[18] Furthermore, several studies concluded that dignity should be the focus of care at the end of life.[19-21] Therefore, considering whether people think their dignity will be undermined if they would be maintained in a certain condition or if their treatment is continued under certain circumstances is important for adequate care planning in life limiting illness. A lack of understanding of a person's wishes about future care might result in a loss of dignity, and additional distress for relatives and health care professionals. As conserving dignity can be considered a goal of palliative care, it might be helpful to get a better understanding of what dignity means to people and whether peoples' perceptions of the importance of dignity at the end of life is affected by health status. A concern that is mentioned by several authors is that patients might change their minds about future treatment preferences when confronted with the actual situation or as their health status changed.[22-24] Therefore, this study aimed to investigate whether health status affects the perceptions of factors influencing personal dignity at the end of life. In addition, we explored the association between the perception of factors influencing personal dignity at the end of life and several socio-demographic characteristics.

Methods

Design and study population

The data for this study were collected within the framework of a Dutch Advance Directives Cohort Study, a major ongoing longitudinal study that aims to describe how advance directives are involved in end-of-life decisions in the Netherlands. The design of the Advance Directives Cohort Study is described in detail by Van Wijmen and colleagues.[25] The study was approved by the Medical Ethics Review Committee of the VU University Medical Center prior to the start of the cohort study in 2005. The cohort consisted of people with one or more of the most common standard advance directives in the Netherlands: 4,496 people who had one or more advance directives (the advance euthanasia directive, refusal of treatment document, and/or appointment of a health care representative) formulated by the NVVE (Right to Die-NL), and 1,261 people who had a wish to live statement (stating the wish to receive adequate care directed at quality of life, and explicitly against euthanasia) provided by the Dutch Patient Association. A written structured questionnaire is sent to the cohort every one and a half years. This study is based on the second data-collection cycle for which data were collected in the Spring of 2007. The response rate in the second data-collection cycle was 88% and 90% for the NVVE members and the members of the Dutch Patients Association, respectively (see Figure 1). In order to analyse the construct of dignity and to assess the content validity of the Patient Dignity Inventory (PDI) prototype we randomly split the cohort into two subsamples of which one received a questionnaire including an open ended question concerning factors relevant to dignity and the other half received a questionnaire including the PDI.[26] The present study focuses on a subsample of the cohort in which dignity was assessed through the PDI, and who completed more than 15 of all 22 items (n=2282).

Figure 1 Flow chart of recruitment and response rates



[a] This number refers to people who had drawn up an AD by the Right to Die-NL, people who requested and not (yet) formulated an AD were not included in this number (n=1065).

[b] A randomly selected half of the cohort received a questionnaire that included the PDI; the other half of the cohort received a questionnaire that included an open-ended question on dignity. Therefore 1865 and 539 people respectively members of the Right to Die-NL and people with a wish to live statement were excluded from this study.

Measurement instrument

The questionnaire consisted of questions on background characteristics, self-perceived health status, and included a question that asked the respondents whether they had an illness such as rheumatism, asthma, heart disease, multiple sclerosis. The Euroqol-5D (EQ-5D)[27] was included to measure whether there were no, some or severe limitations on the following five dimensions: mobility, self-care, activities of daily living (ADL), pain/discomfort, and anxiety/depression. In addition, the questionnaire contained the PDI prototype including 22 items on symptoms and experiences.[18, 26] The PDI prototype preceded the 25-item PDI.[28] Respondents were asked to rate the extent to which they thought that these items would influence their sense of dignity during the last phase of life on a 5-point scale (1=not at all; 2=slightly; 3=somewhat; 4=to a large extent; 5=to a very large extent).

Analyses

We defined the health status groups by use of the EQ5D-items combined with the question on whether the respondents had an illness. The reason for defining the health status groups in this way is that illness-related concerns such as dependence and symptom distress may influence personal dignity at the end of life [29] rather than the illness itself or the type of illness. First, the good health status group consisted of patients who had no illness or impairment regarding mobility, self-care, ADL, pain/discomfort, and anxiety/depression. Second, the moderate health status group consisted of patients who indicated that they had an illness and/or were somewhat impaired in at least one of the EQ-5D items. The last group, the poor health status group, consisted of patients who indicated that they were severely impaired in at least one of the EQ-5D items. Descriptive statistics were used to describe the characteristics of the respondents. We dichotomized the five response categories of the PDI items by combining response options 1 to 3 (1=not at all; 2=slightly; 3=somewhat) and response options 4 and 5 (4=to a large extent; 5=to a very large extent). Percentages of people who indicated that the items could influence the sense of dignity to a large or very large extent (rated a 4 or 5 on the 5-point scale) were presented for three different health status groups. Logistic regression analyses were performed to determine if there was a relationship between considering the PDI items as influential to dignity in the last phase of life and health status. We controlled for the factors that were significantly different over the health status groups. In order to explore if there were any other factors associated with the perceived importance of the PDI items a backward multiple logistic regression (removal at $p<0.05$) was performed and odds ratios were calculated. The following factors were entered in the analysis: sex, age, having a partner, living at home, religion, and self-reported health status. The independent variables have been dichotomized for this analysis. Then separate logistic regression models were fitted for each item of the PDI. All analyses were performed using SPSS 14.0.

The present study focused only on the people who completed at least 15 of the 22 PDI-items which was 90% of the subsample of the cohort who received the questionnaire including the PDI. Though the excluded people were most comparable with the 'moderate health status group' regarding socio-demographic characteristics 13 percent would have been included in the poor health status group. The main difference was that 54 percent of the people excluded from this study indicated that they had a belief or religion that they considered important in their life compared to 37, 35 and 43 percent in the good, moderate and poor health status groups respectively.

Results

Table 1 presents the characteristics of the respondents. The majority of the respondents had a moderate or good health status. People with a poor health status were more likely to be female (71%) and older (mean age 71) compared to people with a good health status (59% female, mean age 61). In addition, people with a poor health status less frequently had a partner, and their place of residence was more frequently a nursing home or care home. People with a moderate or poor health status suffered most often from rheumatoid arthritis, heart disease and depression, followed by asthma/COPD and cancer. Respectively 26 and 77 percent of people with a moderate and poor health status assessed their personal health as less than good.

Table 1 Characteristics of People with an Advance Directive per Health Status Group

Characteristics	**Good health status n=719**	**Moderate health status n=1433**	**Poor health status n=130**
Sex, female (%)*	59	61	71
Age, mean (SD) [range]*	61 (14) [17-91]	61 (12) [25-98]	71 (15) [36-93]
Having a partner (%)*	73	58	45
Residence (%)*			
At home	98	92	76
Institution (e.g. nursing home, care home)	-	2	12
Other (e.g. sheltered accommodation)	2	6	12
Having a belief/religion considered as important in one's life	37	35	43
Diseases (%)*			
Rheumatoid arthritis	-	30	35
Hart disease	-	21	25
Depression	-	6	18
Asthma/COPD	-	11	13
Cancer	-	8	10
Diabetes	-	11	15
Stroke	-	4	11
Multiple Sclerosis	-	-	5
Dementia	-	-	2
Self-reported health status (%)*			
Very good	40	12	3
Good	59	62	20
Less than good	1	26	77

* Significantly different over the health status groups ($p<0.05$)

Table 2 shows the percentages of people with a good, moderate and poor health status who considered the items influencing personal dignity at the end of life to a (very) large extent.

The percentages of people in each health status group who indicated the items as influential to dignity were not significantly different, except for three items included the physical domain: 'Not being able to continue with usual routines', 'experiencing distressing symptoms', 'not being able to carry out important roles'. These items were considered significantly more often as important to dignity by people with a moderate and poor health status compared to people with a good health status, after controlling for gender, age, residence and having a partner.

Table 2 Aspects onsidered Relevant for the Sense of Dignity at the End of Life per Health Status Group

	Good health status n=719	Moderate health status n=1433	Poor health status n=130
	%	%	%
Physical aspects			
Not being able to independently manage bodily functions	63	67	60
Not being able to carry out tasks of daily living	49	52	51
Not being able to continue with usual routines*	36	44	47
Experiencing distressing symptoms*	32	38	45
Not being able to carry out important roles*	25	27	41
Changes in physical appearance	12	14	17
Psychological aspects			
Not being able to think clearly	68	69	64
Not being able to mentally fight$^{\sigma}$	59	61	64
Feeling depressed or anxious	50	49	50
Not being able to accept things the way they are	40	44	50
Social aspects			
Feeling a burden to others	65	70	67
Not being treated with respect or understanding	51	55	50
Feeling your privacy has been reduced	43	48	47
Not feeling supported by your community	44	44	43
Existential aspects			
Feeling you do not have control over your life	59	61	62
No longer feeling like who you were	55	56	60
Feeling life no longer has meaning or purpose	51	53	55
Not feeling worthwhile or valued	41	44	44
Uncertainty regarding illness	30	32	36
Not having a meaningful spiritual life	33	36	33
Not feeling you made a meaning or lasting contribution	21	23	30

* Significant difference between the health status groups after controlling for sex, age, having a partner and living at home (p<0.05)

$^{\sigma}$ 606 missing cases for this item since this item was not included in the questionnaire that was sent to the people who were member the Dutch Patient Association.

Table 3 shows the determinants of considering the items as having a large influence on personal dignity in the last phase of life. Female respondents were more likely than male respondents to rate the items as important except for the physical items. Respondents under the age of 80 had a higher chance of considering the items as influential to the sense of dignity at the end of life. Not having a partner was associated with a higher score on all physical PDI items. People who had a belief or religion that was important in their life were generally less likely to think that the items influence the sense of dignity at the end of life.

Self-reported health status assessed as 'less than good' was significantly associated with two physical PDI items: 'experiencing distressing symptoms' and 'not being able to carry out important roles'.

Table 3 Importance of the PDI items for the Sense of Dignity at the End of Life* (Odds ratio's)

	Female sex	Age <80	Not having a partner	Living at home	Having a belief/religion important in one's life	Self-reported health status (less than good)
Physical aspects						
Not being able to independently manage bodily functions	-	1.5	1.3	-	.33	-
Not being able to carry out tasks of daily living	.78	1.3	1.2	-	.38	-
Not being able to continue with usual routines	-	-	1.5	-	.52	-
Experiencing distressing symptoms	-	1.4	1.7	-	-	1.5
Not being able to carry out important roles	-	-	1.3	-	.67	1.5
Changes in physical appearance	1.4	-	1.5	-	1.3	-
Psychological aspects						
Not being able to think clearly	1.3	1.3	-	-	.50	-
Not being able to mentally fight$^{\sigma}$	1.5	1.4	1.2	1.4	.66	-
Feeling depressed or anxious	1.3	1.5	-	-	.86	-
Not being able to accept things the way they are	1.3	-	-	-	.73	-
Social aspects						
Feeling a burden to others	1.7	-	1.2	-	.44	-
Not being treated with respect or understanding	1.9	1.5	-	-	1.2	-
Feeling your privacy has been reduced	2.0	1.3	1.3	-	.71	-
Not feeling supported by your community	2.0	1.3	.82	-	1.2	-
Existential aspects						
Feeling you do not have control over your life	1.2	1.4	-	-	.39	-
No longer feeling like who you were	1.3	-	-	-	.75	-
Feeling life no longer has meaning or purpose	1.3	1.4	-	.66	.48	-
Not feeling worthwhile or valued	1.7	1.3	-	-	-	-
Uncertainty regarding illness	1.4	-	1.3	-	1.3	-
Not having a meaningful spiritual life	-	-	1.3	-	1.5	-
Not feeling you made a meaning or lasting contribution	-	-	1.2	-	-	-

* Separate logistic regression models were fitted for each PDI item. Odds ratio's are presented in the table when significantly different (P ≤ .05) from the null value.

\- Entered in the regression but not significant and consequently eliminated by the stepwise procedure.

$^{\sigma}$ 606 missing cases for this item since this item was not included in the questionnaire that was sent to the people who were member the Dutch Patient Association.

Discussion

Limited differences were found when comparing how people in good health and people with a poor health status perceive factors important in maintaining dignity nearing the end of life. Three physical items were significantly more often considered as influential to dignity by people with a poor health status. Self-reported health was also not found to be an important determinant except for perceptions on two physical items on symptoms and roles. Gender, old age, having a partner and having a belief or religion that is important to one's life were shown to be the most important determinants regarding the perceptions of factors influential to dignity.

Strengths and limitations

An important strength of this study is that this is a large-scale study. Therefore, it was possible to sub-divide the cohort into three different health status groups. Another strength is that this was the first study that investigated and compared the views on maintaining dignity at the end of life of people with a good health status and people with a poor health status. The study population comprised people with an advance directive, which may be considered a strength because we believe that the quality of the data is enhanced by the fact that the respondents are likely to have thought deeply about end-of-life issues and their life values. On the other hand, it might be argued that this limits the generalisability of the results to other populations. Furthermore, a limitation is that this study did not directly examine whether the perceptions of maintaining dignity at the end of life remain stable over time. The current study was cross-sectional and compared the factors between persons with good, moderate and poor health status. Longitudinal research is needed to investigate the individual stability of the perceptions of factors influencing personal dignity.

The influence of health status on perceptions of personal dignity at the end of life

Perceptions on the psychological, social and existential factors influencing dignity at the end of life seem not to be affected by health status. However, health status seems to have an effect on perceptions of physical factors that would influence dignity in the last phase of life. The results of the current study imply that people with a poor health status are significantly more likely to perceive distressing symptoms, the ability to continue with usual routines, and the ability to carry out important roles as more important than those with a good health status. This would suggest that healthy people tend to underestimate the physical aspects that were found to be influential to dignity at the end of life. The results also suggest that people do not change their mind about the importance of psychological, social and existential factors when their health status changes. Therefore, several authors 16-18 may overestimate the extent to which patients change their minds about life values and preferences for care when confronted with a serious illness or over the course of an illness trajectory regarding the psychological, social and existential factors influencing dignity at the end of life.

The influence of socio-demographic factors on perceptions of personal dignity at the end of life

Socio-demographic characteristics seem to have more influence on how people understand maintaining dignity than health status does. First, it seems that old age (80+) makes people think that the PDI items have not much influence on maintaining dignity at the end of life. This may be explained by the idea that older people found meaning to, and acceptance of, their lives; making them less anxious to die than younger people and less worried about maintaining dignity at the end of life.[30,31] Females are more likely to consider items as important to maintaining dignity, especially the social and psychological items. This finding is in line with a study on health related quality of life in cardiac patients in which it was shown that social support is an important determinant of quality of life among women,[32] and another qualitative study that found that women more specifically described psychological and social issues as challenges in living with an ostomy than men who survived colorectal cancer.[33] Not having a partner is an important determinant, which is not unexpected as a partner is often close by to give support. Overall, people who consider religion important in their life are less likely to believe that the PDI items have any influence on maintaining dignity at the end of life. This finding could be attributed to the common religious belief that no one but God has the authority to determine life and death, and accordingly, religious people believe that they can not influence their situation and their dignity at the end of life.

In conclusion, a poor health status is not associated with different perceptions of factors influencing dignity at the end of life than a good health status, except for the perceptions of some physical factors. Socio-demographics characteristics like gender, religion, age and having a partner are more associated with people's perceptions of factors that influence personal dignity at the end of life than health status or self-reported health. Our findings might suggest that the understanding of dignity will not substantially change as health status changes. This would imply that the perceptions of factors influencing someone's sense of personal dignity can already be discussed in good health or in an early stage of a disease. In light of advance care planning this might contribute to adequate patient centred and dignity conserving care at the end of life. However, further longitudinal research is needed to confirm that people's views on dignity remain stable during the trajectory of illness.

Reference List

1. Davies E, Higginson IJ, eds. Better palliative care for older people. Geneva: World Health Organization, 2004.
2. Carone G, Costello D. Can Europe afford to grow old? International Monetary Fund Finance and Development Magazine 2006;43(3):28-31.
3. Garavan R, Winder R, McGee H, O'Boyle C. HeSSOP Health and Social Services for Older People Summary. Dublin, Ireland: The National Council on Ageing and Older People; 2000.
4. Gruenberg EM. The failures of success. Milbank Mem Fund Q Health Soc 1977;55(1):3-24.
5. Olshansky SJ, Rudberg MA, Carnes BA, Cassel CBJ. Trading off longer life for worsening health. J Aging Health 1991;3(2):194-216.
6. Verbrugge LM. Longer life but worsening health? Trends in health and mortality of middleaged and older persons. Milbank Mem Fund Q Health Soc 1984;62(3):475-519.
7. Ganzini L, Nelson HD, Schmidt TA, et al. Physicians' experiences with the Oregon Death with Dignity Act. N Engl J Med 2000 Feb 24;342(8):557-563.
8. Haverkate I, Onwuteaka-Philipsen BD, van Der Heide A, et al. Refused and granted requests for euthanasia and assisted suicide in the Netherlands: interview study with structured questionnaire. BMJ 2000;321(7265):865-866.
9. Jansen-van der Weide MC, Onwuteaka-Philipsen BD, van der WG. Granted, undecided, withdrawn, and refused requests for euthanasia and physician-assisted suicide. Arch Intern Med 2005;165(15):1698-1704.
10. Meier DE, Emmons CA, Wallenstein S, et al. A national survey of physician-assisted suicide and euthanasia in the United States. N Engl J Med 1998;338(17):1193-1201.
11. Van der Brugghen J, Rurup ML. '' I want my wish to be respected": A study on reasons to formulate an advance directive and expectation of people who recently formulated an advance directive. Amsterdam. The Netherlands. VU University Medical Center, 2006.
12. Baillie L. Patient dignity in an acute hospital setting: a case study. Int J Nurs Stud 2009;46(1):23-36.
13. Enes SP. An exploration of dignity in palliative care. Palliat Med 2003;17(3):263-269.
14. Franklin LL, Ternestedt BM, Nordenfelt L. Views on dignity of elderly nursing home residents. Nurs Ethics 2006;13(2):130-146.
15. Hall S, Longhurst S, Higginson I. Living and dying with dignity: a qualitative study of the views of older people in nursing homes. Age Ageing 2009;38(4):411-416.
16. Matiti MR, Trorey GM. Patients' expectations of the maintenance of their dignity. J Clin Nurs 2008;17(20):2709-2717.
17. Pleschberger S. Dignity and the challenge of dying in nursing homes: the residents' view. Age Ageing 2007;36(2):197-202.

18. Chochinov HM, Krisjanson LJ, Hack TF, et al. Dignity in the terminally ill: revisited. J Palliat Med 2006;9(3):666-672.
19. Brant JM. The art of palliative care: living with hope, dying with dignity. Oncol Nurs Forum 1998;25(6):995-1004.
20. Coppens M. "Death with dignity". Am J Nurs 1998;98(12):23.
21. Latimer E. Caring for seriously ill and dying patients: the philosophy and ethics. CMAJ 1991;144(7):859-864.
22. Kohut N, Sam M, O'Rourke K, et al. Stability of treatment preferences: although most preferences do not change, most people change some of their preferences. J Clin Ethics 1997;8(2):124-135.
23. Silverstein MD, Stocking CB, Antel JP, et al. Amyotrophic lateral sclerosis and lifesustaining therapy: patients' desires for information, participation in decision making, and life-sustaining therapy. Mayo Clin Proc 1991;66(9):906-913.
24. Weissman JS, Haas JS, Fowler FJ, Jr., et al. The stability of preferences for life-sustaining care among persons with AIDS in the Boston Health Study. Med Decis Making 1999;19(1):16-26.
25. van Wijmen MP, Rurup ML, Pasman HR, Kaspers PJ, Onwuteaka-Philipsen BD. Design of the Advance Directives Cohort: a study of end-of-life decision-making focusing on advance directives. BMC Public Health 2010;10:166.
26. Albers G, Pasman HR, Rurup ML, de Vet HC, Onwuteaka-Philipsen BD. Analysis of the construct of dignity and content validity of the Patient Dignity Inventory. Health Qual Life Outcomes 2011;9(1):45.
27. EuroQol--a new facility for the measurement of health-related quality of life. The EuroQol Group. Health Policy 1990;16(3):199-208.
28. Chochinov HM, Hassard T, McClement S, Hack T, Kristjanson LJ, Harlos M, Sinclair S, Murray A. The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care. J Pain Symptom Manage 2008; 36(6):559-71.
29. Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. Soc Sci Med 2002;54(3):433-443.
30. Cicirelli VG. Older adults' views on death. New York: Springer, 2006.
31. Johnson CL, Barer BM. Life beyond 85 years: The aura of survivorship. New York: Springer; 1997.
32. Grant M, McMullen CK, Altschuler A, et al. Gender differences in quality of life among long-term colorectal cancer survivors with ostomies. Oncol Nurs Forum 2011;38(5):587-596.
33. Emery CF, Frid DJ, Engebretson TO, et al. Gender differences in quality of life among cardiac patients. Psychosom Med 2004;66(2):190-197.

Chapter 7

Personal dignity in the terminally ill from the perspective of caregivers: a survey among trained volunteers and physicians

Gwenda Albers, Henrica CW de Vet, H Roeline W Pasman, Luc Deliens, Bregje D Onwuteaka-Philipsen

Submitted

Abstract

Background
Although dignity is increasingly considered as a goal of palliative care, little research evaluated the understanding of dignity at the end of life from a caregivers perspective. Objective: To investigate and compare the views of trained volunteers and SCEN physicians on maintaining dignity for patients reaching the end of life.

Design
Survey questionnaire study.

Subjects
Two groups of caregivers involved in care for dying patients: trained volunteers (n=236) and end-of-life consultants (SCEN-physicians; n=427).

Measurements
Dutch version of the 22-item Patient Dignity Inventory on symptoms and experiences that have been shown to influence the sense of dignity in terminally ill patients Respondents were asked to rate (5-point scale) the extent to which they considered the items as influential to dignity in terminally ill patients, and as problematic in practice to maintain dignity for patients in the last phase of life.

Results
Overall, volunteers indicated the items more frequently as influential to dignity, and as problematic in practice to maintain dignity at the end of life compared to SCEN-physicians. There are some differences in the relative importance of items according to volunteers and SCEN-physicians. It seems that SCEN-physicians consider the physical aspects of suffering as most influential and problematic in practice to preserving dignity while volunteers think psychosocial aspects are most important to preserve dignity at the end of life.

Conclusions
This study suggests that the role and responsibilities of caregivers involved in the care for terminally ill patients affect the factors that they think that influence dignity.

Introduction

The interest in dignity at the end of life has significantly increased in the past decade. This is probably due to the fact that empirical research has shown that loss of dignity is an important concern for patients at the end of life,[1-3] and that several authors have argued that dignity should be considered as a central principle in palliative care.[4-6]

Dignity is important to 92% of the Dutch general public when asked what they consider as important in their dying phase.[7] In addition, loss of dignity is one of the most common reasons to formulate an advance directive,[8] and one of the most frequently mentioned reasons for requesting euthanasia or physician-assisted suicide in the Netherlands.[2,9]

Despite that dignity is a 'hot topic' in discussions about death and dying, and about euthanasia and end of life care, there are only a few studies addressing factors which support or undermine personal dignity at the end of life. Chochinov and colleagues performed a qualitative study to understand how dying cancer patients understand and define dignity which resulted in the development of an empirical model of dignity in terminally ill.[10] This model served as a basis for the development of the PDI prototype, a list of 22 items on symptoms and experiences that influence the sense of dignity.[11] The PDI prototype was later revised into the 25-item Patient Dignity Inventory (PDI), a measurement instrument aiming to detect dignity related distress in patients at the end of life.[12]

Since one of the main goals of end-of-life care is to maintain dignity, caregivers should provide dignified care, and should attend to factors supporting personal dignity in patients near the end of life. However, no studies have investigated how caregivers involved in the provision of palliative care understand dignity in patients near the end of life. Terminally ill patients are often not able to communicate about their preferences for end-of-life care and what supports their personal sense of dignity. As a consequence, family or caregivers might get involved in a complex decision-making process and might need to set priorities for care. Therefore, it is valuable to get insight in how caregivers understand personal dignity in terminally ill patients. In addition, it is of interest to consider which factors hinder the maintenance of dignity in practice from the view of caregivers experienced in care giving at end of life.

Volunteers can play a valuable role in caring for dying patients. Volunteers could give family members respite breaks from care giving which may help say goodbye and support the patient to die with dignity. In addition to volunteers 'Support and Consultation on Euthanasia (SCEN) physicians' can play an important role in the care for terminally ill patients. SCEN physicians provide an important role in case of a request for euthanasia or physician-assisted suicide. SCEN physicians provide their colleagues with information and advise about euthanasia and judge whether the request is in accordance with the euthanasia law which also invokes considerations of dignity.

The aim of this study is to investigate and compare the views of trained volunteers and SCEN physicians on maintaining dignity for patients reaching the end of life.

Methods

Study design and study population

A written structured questionnaire was distributed amongst two groups of caregivers with experience in caring for terminally ill patients. The first group consisted of trained volunteers providing care to dying patients at home or in a hospice who were members of the National Organisation of Volunteers in Palliative Terminal Care (VPTZ).[13] Most of the volunteers have personal and professional experience in care giving at the end of life and all of them are being trained regularly by the VPTZ. Volunteers who attended a congress organised by the VPTZ in fall of 2006 were asked to complete a written questionnaire including questions on dignity.

The other group consisted of SCEN-physicians who participate in a formal network of trained consultants. Next to their work as practicing physician they provide their colleagues with information and expert advice concerning all aspects of euthanasia.[14] The Dutch euthanasia law stipulates that consultation of another physician is required in the case of a euthanasia request, consequently the SCEN-physician has to visit the patient and has to judge whether the request for euthanasia is in accordance to the criteria for due care, which means that they assess whether the patient's suffering is unbearable and without prospect of improvement.[15] SCEN-physicians provide about seven consultations per year, and mostly for patients receiving home care.[16] SCEN-physicians receive a short questionnaire that serves as monitoring device of their activities for the SCEN network of consultants every year. In January 2007 all 497 SCEN-physicians were sent a questionnaire including questions on dignity.

Measurement instrument

This study was based on the PDI-prototype described in the introduction including 22 items covering the following domains: physical, psychosocial, social and existential.[12] The extent to which the respondents thought that the items have influence on maintaining patients personal dignity in the last phase of life were rated on a 5-point scale (1=not at all; 2=slightly; 3=somewhat; 4=to a large extent; 5=to a very large extent). The PDI items were introduced by the following text: 'The term dignity is often used when talking about the last phase of life. However, little is known about how dignity is understood. Because of your experience in providing care to patients near the end of life, we are very interested in how you understand dignity.' Then, the respondents were asked: Could you please rate (based on your experience) the extent to which you think that the following items 1) influence the sense of personal dignity in patients in the last phase of life?, and 2) make it problematic in practice to maintain personal dignity in patients in the last phase of life? For the purpose of this study the items were translated into Dutch by means of forward and back translation. The respondents were also asked whether they thought that there were any factors missing which could influence patients sense of dignity during the last phase of life.

Analysis

First, we examined whether each PDI-item was considered influential to personal dignity in terminally ill patients, and second, whether the items were seen as factors that can make it problematic maintaining dignity in practice by calculating the percentage of volunteers and SCEN-physicians who scored 4 or 5 on the 5-point scale per item. In addition, the items were ordered and ranked per domain to enable comparison of the findings between caregiver groups. Differences in rating between volunteers and SCEN-physicians were described using 95% confidence interval. Furthermore, we constructed a top 10 list per caregiver group, to show which items were the most frequently considered as influential to the sense of personal dignity and which items were the most often considered as a factor that can make it problematic to preserve dignity in practice.

Results

A total of 236 volunteers completed the questionnaire. This group of volunteers consisted of 4% of all members of VPTZ and was a representative sample of all members with regard to sex, however, the respondents were somewhat older (mean age: 59.5) compared to all volunteer members of the VPTZ (mean age: 54,8). Of the SCEN-physician 427 (86%) responded to the questionnaire.

Factors relevant to patients' personal dignity

Table 1 shows the percentage of volunteers and SCEN-physicians who indicated that the PDI-items influence the sense of dignity in patients at the end of life to a (very) large extent. For all but one item, "not being able to think clearly", SCEN-physicians gave lower scores than volunteers. For some items there were only slight differences, but for twelve items there were statistical significant differences. More than 50% of the volunteers and the SCEN-physicians considered the following items as having influence on sense of dignity in terminally ill patients: "not being able to independently manage bodily functions", "not able to think clearly", "feeling a burden to others", "feeling you do not have control over your life" and "no longer feeling like who you were". Eight other items were considered as having influence on sense of dignity in terminally ill patients by more than 50% of the volunteers. Two items were thought to have influence on sense of dignity by only 10% and 15% of the SCEN-physicians; "thinking how life might end" and "uncertainty regarding illness". The item "not having a meaningful spiritual life" was endorsed the least by volunteers (29%) as having influence on sense of dignity. The items within each domain have been ranked very similar for both groups of respondents, and the items in the social domain have been ranked in exactly the same order. The main difference was found in the ranking of the items in the psychological domain: the item "not being able to accept things the way they are" has been ranked at first by relevance to dignity according to volunteers and ranked at third according to SCEN-physicians (59% and 31%).

Table 1 Influence of Physical, Psychological, Social and Existential Aspects on Sense of Dignity in Terminally ill Patients according to trained Volunteers and SCEN-physicians[1]

	Trained volunteers			SCEN-physicians		
	n=236[2]			n=427[3]		
	%	Rank[4]	95% CI	%	Rank[4]	95% CI
Physical aspects						
Not being able to independently manage bodily functions	69	1	63-75	67	1	62-72
Changes in physical appearance*	52	2	45-58	28	5	24-32
Experiencing distressing symptoms	51	3	44-58	49	2	44-54
Not being able to carry out important roles	45	4	38-51	36	3	31-41
Not being able to carry out tasks of daily living	42	5	36-49	34	4	29-38
Not being able to continue with usual routines*	41	6	34-47	16	6	12-19
Psychological aspects						
Not being able to accept things the way they are*	59	1	52-65	31	3	26-35
Not being able to think clearly	54	2	47-60	55	1	50-60
Feeling depressed or anxious*	51	3	44-58	29	4	25-34
Not being able to mentally fight	47	4	40-53	38	2	33-43
Social aspects						
Feeling a burden to others*	70	1	64-76	54	1	50-59
Feeling your privacy has been reduced*	58	2	51-64	44	2	39-49
Not being treated with respect or understanding*	58	3	52-65	33	3	29-38
Not feeling supported by your community*	43	4	37-50	24	4	20-29
Existential aspects						
Feeling you do not have control over your life	66	1	59-72	62	1	57-67
No longer feeling like who you were	61	2	55-68	53	2	48-58
Not feeling worthwhile or valued*	60	3	53-66	45	3	41-50
Feeling life no longer has meaning or purpose	53	4	46-59	44	4	39-49
Not feeling you made a meaningful or lasting contribution*	46	5	39-52	24	6	20-29
Thinking how life might end*	39	6	33-46	15	7	12-19
Uncertainty regarding illness*	37	7	31-44	10	8	7-13
Not having a meaningful spiritual life	29	8	22-35	26	5	22-31

* Significant difference between volunteers and SCEN-physicians

[1] Percentage that score 4 (to a large extent) or 5 (to a very large extent) on a scale of 1 to 5

[2] Between 7 and 33 missing observations per aspect

[3] Between 18 and 34 missing observations per aspect

[4] Ranking from first to last of the aspects per each of the 4 categories

Factors that can make it problematic in practice maintaining patients' dignity

Table 2 shows the percentage and ranks of volunteers and SCEN-physicians who considered that the presence of the PDI-items in patients reaching the end of life make it problematic in practice maintaining dignity. Again, SCEN-physicians generally scored lower on the items being problematic maintaining dignity in practice compared to volunteers. The percentages significantly differ between the two respondent groups for 10 items, including three of the four social items. The following items have been considered as items that can make it problematic in practice maintaining dignity in terminally ill patients by 50% or more of the SCEN-physicians and volunteers: "not being able to independently manage bodily functions", "not being able to think clearly", "feeling you do not have control over your life". No striking differences have been found comparing the ranking of the items per domain for the volunteers and SCEN-physicians.

Table 2 Extent to which the Physical, Psychological, Social and Existential Aspects are in Practice Problematic for Terminally ill Patients maintaining their Sense of Dignity according to Trained Volunteers and SCEN-physicians[1]

	Trained volunteers			SCEN-physicians		
	n=236[2]			n=427[3]		
	%	Rank[4]	95% CI	%	Rank[4]	95% CI
Physical aspects						
Not being able to independently manage bodily functions	58	1	51-65	56	2	51-61
Experiencing distressing symptoms	46	2	38-53	57	1	42-52
Not being able to carry out tasks of daily living	44	3	37-51	34	3	29-39
Not being able to continue with usual routines*	35	4	28-42	18	6	14-22
Not being able to carry out important roles	33	5	26-40	27	4	22-31
Changes in physical appearance	22	6	18-26	22	5	18-26
Psychological aspects						
Not being able to think clearly	54	1	47-61	56	1	51-61
Not being able to accept things the way they are*	51	2	44-58	35	2	31-40
Feeling depressed or anxious*	46	3	39-53	33	4	28-38
Not being able to mentally fight	38	4	31-45	35	3	30-39
Social aspects						
Feeling a burden to others	60	1	53-67	48	1	43-53
Feeling your privacy has been reduced*	56	2	48-63	39	2	34-44
Not being treated with respect or understanding*	54	3	47-61	31	3	27-36
Not feeling supported by your community*	43	4	36-50	20	4	16-24
Existential aspects						
Not feeling worthwhile or valued*	54	1	46-61	35	4	30-40
Feeling you do not have control over your life	50	2	43-57	50	1	45-55
No longer feeling like who you were	49	3	42-56	41	3	36-46
Feeling life no longer has meaning or purpose	40	4	33-46	45	2	40-50
Thinking how life might end*	36	5	29-43	15	7	12-19
Uncertainty regarding illness*	34	6	28-41	13	8	9-16
Not feeling you made a meaningful or lasting contribution*	30	7	24-37	19	6	14-23
Not having a meaningful spiritual life	20	8	14-25	21	5	17-25

* Significant difference between volunteers and SCEN-physicians

[1] Respondents were asked to name the three aspects the most problematic in practice

[2] Between 43 and 62 missing observations per aspect

[3] Between 37 and 51 missing observations per aspect

[4] Ranking from first to last of the aspects per each of the 4 categories

Top 10 PDI-items most influential and problematic

Table 3 shows the 10 items most frequently scored as having influence on sense of dignity and the 10 items most often scored as problematic to maintain dignity in practice according to volunteers and SCEN-physicians.

Volunteers considered 8 items as influential as well as problematic in practice. However, the item "feeling you do not have control over life" is more often considered as influential than as problematic in practice (3rd ranked versus 8th rank), and "feeling your privacy has been reduced" is considered more often as problematic in practice than influential on dignity (3rd ranked versus 7th ranked). SCEN-physicians considered 9 similar items most frequently as influential as well as problematic in practice. Once more, the ranking of these items do differ, for example "experiencing distressing symptoms" has been considered more often as an item that can make it problematic to maintain dignity in practice (1st ranked) than it has been considered as influential to dignity (ranked as 6th).

Six items are included in all 4 columns of Table 3: "feeling a burden to others", "not being able to independently manage bodily functions", "feeling you do not have control over your life", "not feeling worthwhile or valued", "feeling your privacy has been reduced" and "not being able to think clearly". These items are considered as influential as well as problematic in practice by volunteers and SCEN-physicians. In all 4 columns the four domains, physical, psychological, social and existential domain, are represented, though rankings and the number of items per domain differ over the 4 columns. For instance, there are 3 social items included in both columns representing the items most often considered as influential as well as problematic in practice by volunteers, while there are 2 social items included in the columns for SCEN-physicians. In addition, the social items are generally higher ranked by volunteers than by SCEN-physicians.

An interesting finding is that "not being treated with respect or understanding" is only included in the volunteers item top-10, and the item "experiencing distressing symptoms" is only included in the physicians top-10.

Table 3 The Top 10 of Items of Influence to and Problematic in Practice for Sense of Dignity of Terminally ill Patients according to Volunteers and SCEN-physicians

	Volunteers		SCEN-physicians	
Rank*	**Of influence**	**Problematic in practice**	**Of influence**	**Problematic in practice**
1.1.4.5.	Feeling a burden to others [So]	Feeling a burden to others [So]	Not being able to independently manage bodily functions [Ph]	Experiencing distressing symptoms [Ph]
2.2.1.2.	Not being able to independently manage bodily functions [Ph]	Not being able to independently manage bodily functions [Ph]	Feeling you do not have control over your life [Ex]	Not being able to independently manage bodily functions [Ph]
3.8.2.4.	Feeling you do not have control over your life [Ex]	Feeling your privacy has been reduced [So]	Not being able to think clearly [Ps]	Not being able to think clearly [Ps]
4.6.7.10.	Not feeling worthwhile or valued [Ex]	Not being treated with respect or understanding [So]	Feeling a burden on others [So]	Feeling you do not have control over your life [Ex]
5.7.-.9.	Not being able to accept things the way they are [Ps]	Not being able to think clearly [Ps]	No longer feeling like who you were [Ex]	Feeling a burden to others [So]
6.4.-.-.	Not being treated with respect or understanding [So]	Not feeling worthwhile or valued [Ex]	Experiencing distressing symptoms[Ph]	Feeling life no longer has meaning or purpose [Ex]
7.3.8.8.	Feeling your privacy has been reduced [So]	Not being able to accept things the way they are [Ps]	Not feeling worthwhile or valued [Ex]	No longer feeling like who you were [Ex]
8.5.3.3.	Not being able to think clearly [Ps]	Feeling you do not have control over your life [Ex]	Feeling your privacy has been reduced [So]	Feeling your privacy has been reduced [So]
9.-.9.6.	Feeling life no longer has meaning or purpose [Ex]	No longer feeling like who you were [Ex]	Feeling life no longer has meaning or purpose [Ex]	Not being able to accept things the way they are [Ps]
10.-.-.-.	Changes in physical appearance [Ph]	Feeling depressed or anxious [Ps]	Not being able to mentally fight [Ps]	Not feeling worthwhile or valued [Ex]

*These numbers indicate the ranks of the first item in every row. For example, "feeling a burden to others" (rankings: 1.1.4.5.), has been considered most often of influence as well as problematic by volunteers, and SCEN-physicians considered this items the 4th most frequently of influence to dignity and the 5th most frequently as problematic to maintain dignity in practice.

θ The abbreviation between the square brackets refer to the domain that includes the item, [Ph] physical domain, [Ps] psychological domain, [So] social domain, [Ex] existential domain

Other aspects relevant to sense of dignity

Issues that volunteers described more than a few times as issues relevant to sense of dignity but not represented in PDI-items were: getting attention and acknowledgement for their problems and wishes, being patronized, incontinence (apparently not recognized as covered by the PDI-item 'not being able to independently manage bodily functions'), being cared for by many different caregivers, deterioration of hearing, eyesight or memory.

Issues that were described several times by SCEN-physicians as missing in the PDI were: loss of control of bodily functions, which was often more specifically described as incontinence of bladder and bowel, and the consequences of incontinence described as unsightly appearance and unpleasant smell. Mental deterioration and not being able to communicate was also mentioned more than a few times as missing in the PDI.

Discussion

The present study was conducted to gain more insight into views of caregivers involved in caring for terminally ill patients on maintaining personal dignity for patients reaching the end of life. Therefore, we explored how trained volunteers and SCEN-physicians considered the influence of the PDI-items and the extent to which the items can make it problematic maintaining dignity in practice. Overall, volunteers indicated the items more frequently as influential to dignity, and as problematic in practice to maintain dignity at the end of life compared to SCEN-physicians. However, volunteers and SCEN-physicians have roughly the same perspective on the relevance of the items with regard to dignity in patients near the end of life.

A strength of the current study is the high response of the SCEN-physicians. Nevertheless, this study has a few limitations. First, we do not know the response rate of the volunteers and, the extent to which they are representative for untrained non-professional volunteers involved in the provision of palliative care. Furthermore, the volunteers included in the present study attended a VTPZ congress and, therefore, they might possibly be more involved in their work and care giving at the end of life. They may be better able to imagine which factors influence the sense of dignity in patients in the final phase of life compared to caregivers in general since they have been trained.

Comparing our results to the data from a study by Chochinov et al. terminally ill cancer patients more frequently (strongly) agreed that each item ascribe to sense of dignity.[11] Chochinov's et al. found that the following two social items were the highest ranked items by patients: "feeling a burden to others" and "not being treated with respect or understanding". Our study found that SCEN-physicians did not much ascribe the social items, "not being treated with respect or understanding" in particular. "Experiencing distressing symptoms" was the second last item ascribed as influential to dignity in Chochinov's study, and not included in the items top-10 of the volunteers in the current study while the item was most frequently considered as problematic to maintain dignity in practice by SCEN-physicians. It seems that SCEN-physicians consider the more physical aspects of suffering as most influential to dignity and also as factors that can make it problematic maintaining dignity in practice while volunteers think psychosocial aspects are most important to preserve personal dignity at the end of life. This is in accordance to what Steinhauser and colleagues found from a study on factors considered important at the end of life among patients, family and other care givers[17]. They concluded that physicians tend to focus on physical aspects whereas the perspective of patients and families regarding the end of life is broader focussing also on psychosocial aspects and spiritual meaning[17]. An explanation for what we found in the current study might be that the role of care giving at the end of life differs between volunteers and SCEN-physicians. Volunteers are often more involved in someone's personal life by providing comfort and support to the patient as well as to his or her family and friends, which might impact how volunteers think about the PDI-items with regard to preserving or undermining personal dignity in terminally ill patients. They might possibly be better able to imagine how a situation of terminal illness affect a patient's life and his or her social environment, and consequently what this means to the sense of personal dignity of a patient. Whereas, SCEN-physicians are required by the Dutch euthanasia law to assess the patient's suffering and whether it is unbearable. In addition, since SCEN-physicians see the people who explicitly requested for euthanasia, about 7% of all people who die nonsudden in the Netherlands,[18] they see the more complex medical situations. For these reasons, and in accordance with the study performed by Pasman and colleagues,[19] it seems that physicians focus more on physical suffering.

In accordance to a previous study which explored the construct of dignity and the content validity of the PDI,[20] the present study shows that communication has been considered as an important aspect which is not covered in the PDI. In addition, the respondents of the present study indicated that they missed items in the PDI, like for instance on 'incontinence of bladder and bowel' and 'unsightly appearance and unpleasant smell'. These issues are basically represented, however, by the item 'not being able to independently manage bodily functions'. Since the respondents of the previous study indicated the same issues that are missing in the PDI,[20] it seems even more that the PDI-items might be quite abstract, and that people prefer specifically phrased items like 'not being able to independently get to the toilet' or 'incontinence'.

In conclusion, this study makes an important contribution since there has been done only little research to investigate the caregivers perspective regarding dignity at the end of life. There were found differences in the relative importance of the items according to trained volunteers and SCEN-physicians in the Netherlands. We might conclude that volunteers are more likely to ascribe social factors to sense of dignity while SCEN-physicians are more likely to ascribe physical factors to sense of dignity at the end of life. It seems the role and responsibilities of a caregiver involved in the care for terminally ill patients affect the factors that they think that influence dignity. Since dying with dignity has been considered as a principle goal of palliative care and the PDI-items were developed in accordance to what terminally ill cancer patients perceive that influence dignity, the PDI-items could help to train people providing palliative care and, to attend to these factors to promote and maintain dignity in patients at the end of life.

References

1. Aspinal F, Hughes R, Dunckley M, Addington-Hall J. What is important to measure in the last months and weeks of life?: A modified nominal group study. Int J Nurs Stud 2006 May;43(4):393-403.
2. Jansen-van der Weide MC, Onwuteaka-Philipsen BD, van der WG. Granted, undecided, withdrawn, and refused requests for euthanasia and physician-assisted suicide. Arch Intern Med 2005 Aug 8;165(15):1698-704.
3. Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. N Engl J Med 1998 Apr 23;338(17):1193-201.
4. Brant JM. The art of palliative care: living with hope, dying with dignity. Oncol Nurs Forum 1998 Jul;25(6):995-1004.
5. Coppens M. “Death with dignity”. Am J Nurs 1998 Dec;98(12):23.
6. Latimer E. Caring for seriously ill and dying patients: the philosophy and ethics. CMAJ 1991 Apr 1;144(7):859-64.
7. Rietjens JA, van Der HA, Onwuteaka-Philipsen BD, van der Maas PJ, van der WG. Preferences of the Dutch general public for a good death and associations with attitudes towards end-of-life decision-making. Palliat Med 2006 Oct;20(7):685-92.
8. Van der Brugghen J, Rurup ML. “Ik wil dat mijn wil gerespecteerd wordt”: Onderzoek naar de motivatie om een wilsverklaring op te stellen en de verwachtingen van mensen die recent een wilsverklaring hebben opgesteld. VU University Medical Center, Amsterdam; 2006.
9. Haverkate I, Onwuteaka-Philipsen BD, van Der HA, Kostense PJ, van der WG, Der Maas PJ. Refused and granted requests for euthanasia and assisted suicide in the Netherlands: interview study with structured questionnaire. BMJ 2000 Oct 7;321(7265):865-6.
10. Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. Soc Sci Med 2002 Feb;54(3):433-43.
11. Chochinov HM, Krisjanson LJ, Hack TF, Hassard T, McClement S, Harlos M. Dignity in the terminally ill: revisited. J Palliat Med 2006 Jun;9(3):666-72.
12. Chochinov HM, Hassard T, McClement S, Hack T, Kristjanson LJ, Harlos M, et al. The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care. J Pain Symptom Manage 2008 Dec;36(6):559-71.
13. http://www.vptz.nl/. Accessed 27 june, 2011.
14. http://knmg.artsennet.nl/Dossiers/Dossiers-op-thema/levenseinde/scen.htm. Accessed 27 june, 2011.
15. http://www.euthanasiecommissie.nl/Images/Jaarverslag%202008%20Engels_tcm52-27032.pdf. Accessed 27 june, 2011.
16. Onwuteaka-Philipsen BD, Buiting HM, Pasman HRW, Rurup ML, Willems DL. Evaluatie van SCEN: Wat is goede steun en consultatie? 2010.
17. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA. 2000;284:2476-2482.

18. Onwuteaka-Philipsen BD, Rurup ML, Pasman HR, van Der HA. The last phase of life: who requests and who receives euthanasia or physician-assisted suicide? Med Care 2010 Jul;48(7):596-603.
19. Pasman HR, Rurup ML, Willems DL, Onwuteaka-Philipsen BD. Concept of unbearable suffering in context of ungranted requests for euthanasia: qualitative interviews with patients and physicians. BMJ 2009;339:b4362.
20. Albers G, Pasman HR, Rurup ML, de Vet HC, Onwuteaka-Philipsen BD. Analysis of the construct of dignity and content validity of the Patient Dignity Inventory. Health Qual Life Outcomes 2011 Jun 19;9(1):45.

Chapter 8

General discussion

In this thesis several issues and methodological challenges related to palliative care research are described, and special attention is paid to measuring important concepts in this field i.e. quality of life and personal dignity. The studies described in this thesis all contribute to a better understanding of the current state-of-the art in outcome measurement in palliative care research. The findings of these studies provide helpful information about the difficulties of measuring the complex concepts of quality of life and personal dignity in research on palliative care and can help to direct future research in this field.

This final chapter will discuss the findings of the studies described in the previous chapters. First, some methodological considerations will be addressed. Subsequently, the discussion is divided into three parts corresponding to those presented in the introduction. The main findings and the interpretation of the results will be discussed per part. Implications for research policy and suggestions for further research will also be considered separately per part following on from the discussion of the main findings. Part I addresses the main results and the interpretation of the results concerning the first research question i.e. what is the methodological rigour of palliative care research in long-term care facilities in Europe? The findings related to the feasibility and clinimetric quality of measurement instruments to measure quality of life in palliative care patients will be discussed in Part II. The following paragraphs included in Part III address the findings related to the concept of personal dignity at the end of life and the influence of health status, socio-demographics and the role of caregivers. The final paragraph draws some overall conclusions.

Methodological considerations of the studies

This thesis is based on four different studies: two systematic literature reviews, a survey among people with an advance directive and a survey among caregivers involved in the care for terminally ill patients.

The systematic reviews

The process of systematic review refers to locating, appraising and synthesizing the evidence from all individual studies relevant to a specific research question. Chapter 2 described how a systematic review of the literature was used to explore the field of research on palliative care in long-term care facilities. In this way a comprehensive summary of all European studies on palliative care in long-term care facilities could be given. Recent and adequate information is needed to propose a future research agenda on palliative care research in long-term care facilities in Europe. Since long-term care facilities are increasingly responsible for palliative care the systematic review described in Chapter 2 is useful to provide those professionals with information about state-of-the-art research in this field. Policy makers and even researchers can benefit from an overview of the literature as they often have a lack of time and knowledge to provide themselves with all the latest information. Since palliative care has mainly been associated with patients with specific diseases such as cancer, it might be that study populations in studies on long-term care facilities were not specifically described as palliative care or end-of-life care population[1] in particular because patients residing in long-term care facilities do not often have specific terminal illnesses. Accordingly, a previous study found that there is little similarity between patient groups that were defined as 'end-of-life' patients, and showed the difficulty of defining groups in palliative care research.[2] A consequence might be that not all studies on palliative care populations were indexed as palliative or end-of-life care related studies on the medical databases such as PubMed. Therefore, any relevant studies may not have been found by the search strategy we used in the review study described in Chapter 2.

Chapter 3 and 4 are based on another systematic review that brought together all different measurement instruments to assess quality of life for use in palliative care. This review can be characterised as a clinimetric review as the content and measurement properties of measurement instruments were critically appraised and compared. The clinimetric review on quality-of-life measures can be very helpful for selecting an instrument for a certain purpose, and to identify instruments that need further testing.[3]

Despite the possibility of missing any important studies, frequently mentioned in relation to systematic reviews, it is unlikely that any relevant articles have been missed here. Some experts were consulted in order to develop an adequate search strategy, and a clinimetric search filter with a sensitivity of 90-97% was included.[4] Restriction the search to the English and Dutch languages in both review studies might have limited the results. In addition, as the amount of literature is growing rapidly it might be that from the time our systematic reviews were submitted to a journal new studies were published. In general, systematic reviews are not completely up-to-date at the moment of publication.

The survey studies

Survey research represents one of the most common types of quantitative research in health and social science research. Cross-sectional surveys gather data to make inferences about a population of interest at one moment in time.[5] We used a survey design as a cost-effective and efficient way of gathering information from a large and specific study population and to find relationships between population characteristics and other variables. Data used in the studies described in Chapter 5 and 6 were collected from a large cohort study consisting of more than 6,000 people with an advance directive. An important strength of this large-scale cohort study is that we could divide the cohort into sub-groups that included enough people to perform meaningful statistical analyses of the sub-group. Consequently, we could adequately assess the content validity of the Patient Dignity Inventory since we split the cohort in one group who completed the Patient Dignity Inventory and another group who completed an open-ended question on dignity (Chapter 5). In addition, we were able to define three health status groups in order to investigate the effect of health status on perceptions of factors influencing personal dignity (Chapter 6).

Main concerns about survey research relate to sampling, representativeness and generalizability.[6] The advance directives cohort study was set up by taking random samples from the membership files of the Right to Die-NL and the Dutch Patient Association. The cohort is representative for the part of the Dutch population who formulated an advance directive, although it has to be considered that people who do not have a standard advance directive but draw one up for themselves were not included in the cohort. In addition, comparing the two groups of the cohort to the Dutch population showed several differences regarding background characteristics. The Right to Die-NL respondents were more often single, more highly educated and non-religious.[7] The majority of respondents who were members of the Dutch Patient Association were from a Protestant background.[7] It might be argued that the results of our survey studies cannot be generalised to other populations because people who formulated an advance directive may be considered as people having exceptional views on issues concerning the end of life. Nevertheless, concern about loss of dignity is one of the most common reasons to formulate an advance directive; the respondents may have thought more profoundly about life values and end-of-life issues which makes the advance directives cohort a relevant group for the study of personal dignity. The generalizability of the results described in Chapter 7 can also be criticised. Data for this study was collected in two groups of caregivers, trained volunteer members of the National Organisation of Volunteers in Palliative Terminal Care and Support and Consultation on Euthanasia (SCEN) physicians, with much experience of the issues involved in care at the end of life. Other caregiver respondents may have produced different results. However, we assumed that experience with palliative care made our study population better able to imagine which factors influence the sense of dignity in a patient's final phase of life compared to caregivers in general, which enhances the quality of the data.

Another possible source of bias frequently mentioned in relation to survey studies is the inflexibility of questionnaires that may provide responses that may not accurately reflect how the respondents exactly feel. We used a written questionnaire including the Patient Dignity Inventory consisting of standardised questions. As one of our study aims was to investigate whether the Patient Dignity Inventory comprehensively reflect the construct of personal dignity at the end of life, we created a semi-structured questionnaire by giving the respondents the possibility to indicate what aspects they missed in the Patient Dignity Inventory by an open-ended question. In addition, one half of the cohort received a questionnaire including open-ended questions concerning dignity which demonstrated that open-ended questions provided more detailed information on how the respondents understand dignity at the end of life as they could use more specific phrasing compared to the information gathered from the Patient Dignity Inventory with structured response options provided.

Part I

Research methodology in research on palliative care in long-term care facilities

Life expectancy has been increasing and more people are becoming very old, and will get frail and/or suffer from chronic long-term illnesses.[8] Health care services are facing challenges to provide good care for these frail older people. Moreover, increasingly more people live their final phase of life in long-term care settings and die in these settings. Therefore, exploring and studying the opportunities to provide appropriate palliative care services in long-term care facilities is important.

Key findings and interpretation of the results regarding the methodological rigour of palliative care research in long-term care facilities

Little attention has been paid to research on palliative care in long-term care facilities in Europe, and the majority of the studies of them are descriptive. This can be related to the relatively newness of research on patients receiving palliative care in long-term care facilities, and the methodological difficulties hampering the use of interventions and randomized clinical trials in studies investigating palliative care.[9,10] Another explanation might be that the care given in long-term care facilities is not always considered as palliative care. Residents of long-term care facilities do not usually die from cancer but are more likely to die at an older age from complications associated with multiple chronic diseases.[1] Murray and colleagues described the illness trajectory for people with progressive chronic illness as 'prolonged dwindling'.[11] The illness trajectory typical of frail elderly people or people with dementia entails a short period of evident decline subsequent to a rather stable period with progression.[11] The illness trajectory of cancer is reasonably predictable and usually characterised by a clear terminal phase. The traditional palliative care services concentrated on providing comprehensive services in the last weeks or months of life,[11] and consequently, palliative care has mainly been associated with cancer patients. However, it has been recognised that palliative care should be provided on the basis of needs rather than prognosis or diagnosis.[8] The palliative care approach should be offered increasingly alongside curative treatment to support people with chronic progressive illnesses over many years.[11] As long-term care residents have multidimensional care needs the palliative care approach including psychological and spiritual care would also be an appropriate care approach in long-term care settings.

More research on palliative or end-of-life care in long-term care facilities has been performed in the Netherlands compared with other European countries. A reason may be that the Netherlands is unique with regard to the existence of nursing home medicine as an independent medical specialism.[12] In the Netherlands a nursing home physician is part of the staff in every nursing home. The long tradition of developing the system of long-term care in the Netherlands went along with the involvement of long-term care facilities in various scientific research projects in the past two decades.

Symptoms and symptom management were found to be the most frequently measured outcome in the studies. A previous study that examined the status of palliative care research in Europe also concluded that they were the main area of content of research.[13] However, this may not be surprising as pain and other physical symptoms are more clearly defined and therefore easier to measure compared with psychosocial and spiritual issues. This seems to be reflected by the content of the quality-of-life instruments as the domain of physical comfort was more often included than the other domains of quality of life. Measuring psychosocial or spiritual wellbeing is rather more complicated than measuring the presence of symptoms, though increasing the understanding of psychosocial and spiritual issues in long-term care facilities is of importance to improving research and care in long-term care facilities. For instance, due to lack of agreement on a clear definition and consensus about appropriate outcomes on spirituality, researchers and caregivers are given little guidance on how to assess spiritual needs at the end of life, which is a barrier to the provision of adequate spiritual care at the end of life.[14]

Many different measurement instruments were used in studies on palliative care in long-term care facilities. This may be due to the lack of knowledge about which instruments are valid and most appropriate for use in long-term care facilities. Furthermore, many residents are cognitively impaired, which makes using most instruments very complicated. Consequently, many self-report questionnaires are not useful in these settings. Although studies investigating the agreement between patient and proxy ratings report inconsistent findings[15-17] the use of proxy ratings is of utmost importance in research in these settings because of the high prevalence of dementia.[18,19]

Suggestions for research policy and practice regarding the methodological rigour of palliative care research in long-term care facilities

In order to develop more evidence and to improve research on palliative care in long-term care facilities more uniformity in defining palliative care in these settings needs to be developed. As we described in the introduction, conceptual clarity and clearly defined study populations are of significant importance to operationalizing concepts. Therefore, the development of well-defined and more standardised descriptions concerning the quality of palliative care is needed. In addition, the identification of appropriate outcomes reflecting the concerns of patients receiving palliative care, like for instance, quality of life and dignity, and how these outcomes can best be measured is important. Special attention should be paid to the identification of outcomes and the development and validation of measurement instruments that can be used for proxy assessments. In order to improve palliative care nationally and internationally, organizations for the promotion and development of palliative care, such as the European Association for Palliative Care (EAPC) or the International Association for Hospice & Palliative Care (IAHPC), should support further development and identification of concepts, definitions and outcomes for palliative care research. These organisations should stimulate their use and help to implement the use of more standardised concepts, definitions and outcomes as this would make research more comparable and benefit all researchers working in the field. In addition, clear definitions and valid outcome measures are needed to adequately evaluate interventions in the palliative care setting. Moreover, organisations for research funding should also be aware of the importance of conceptual clarity and adequate and valid measures in order to perform high quality research and evaluate interventions. In order to improve research and to develop adequate evidence-based palliative care, more prospective and longitudinal studies, such as trials and intervention studies to verify hypotheses defined by the descriptive studies conducted in the field, should be developed, although retrospective studies can also provide relevant information and have many practical advantages considering the frailty and short life expectancy of patients receiving palliative care. Furthermore, duplicating or expanding national research projects can be an efficient way to provide more robust evidence, to achieve international collaboration and to make research more comparable across countries in order to facilitate international guideline development, evidence-based care, and policy making.

Part II

Measuring quality of life in palliative care

The primary goal of palliative care is to improve the quality of life of patients and their families. According to the WHO definition of palliative care this means that in addition to physical pain and symptoms attention need to be paid to patients' psychosocial and spiritual concerns.[20] Palliative care may entail any form of medical care or treatment that concentrates on the prevention and relief of suffering. Any combination of pain and symptom management, psychological care and spiritual care, and social support can be applied to improve the quality of life of patients for whom there are no longer any curative treatment options.[21] Quality-of-life measurement is an important aspect of palliative care, given that maximizing the quality of life in terminally ill patients is the main aim of this type of care. Four principal goals supporting the importance of measuring the quality of life and outcomes of care have been described by Hearn and Higginson.[22] First, detailed information about the patient obtained by outcome measurement can be used for clinical monitoring to aid and improve patient care, and to help in decision making.[23] Second, the care provided can be audited by determining whether standards are being achieved and by identifying potential areas for improvement. Third, quality-of-life outcome measures can be used to compare services, or to compare care before and after the introduction of a service in order to assess the efficacy and cost-effectiveness of care services. Finally, analysis of data generated by the use of outcome measures can be used to inform purchasers and thereby secure resources for future services. According to these goals the use of instruments to measure quality of life and care outcomes should be encouraged. A large variety of measurement instruments have been developed and used to measure quality of life in palliative care. However, there is a lack of consensus on what is the most appropriate outcome measure.

Key findings and interpretation of the results regarding the content of the quality-of-life instruments

A first step in the evaluation of the quality-of-life instruments was the development of a quality-of-life framework including domains identified as important to people for whom there are no curative treatment options. Physical comfort, physical functioning, cognitive functioning, psychological, social and spiritual wellbeing and perceived quality of care were identified as the most important domains. Most quality-of-life instruments suitable for use in palliative care covered only one or two of these domains, and none of the instruments covered all quality-of-life domains included in the framework. The domain of physical comfort was the most often included in the quality-of-life instruments. However, it is generally recommended that health-related quality-of-life should be assessed using a multidimensional instrument rather than by using one or more unidimensional instruments assessing one particular domain of quality of life.[24] Thus, the outcome measures should be comprehensive and reflect the specific goals of palliative care. Dame Cicely Saunders advocated that people are indivisible physical and spiritual beings.[25] In addition, several studies showed that spiritual and existential issues become more and more important at the end of life,[26-30] and the existential or spiritual domain has also been found to be an important determinant of quality of life in palliative care settings.[31] However, many health-related quality-of-life measures may be criticised for being too narrow by mainly focusing on physical, psychological and social aspects of a patient's life. Since the concept of spirituality has not been very well defined, we hypothesised that the domain of spirituality was rarely included in the quality-of-life instruments. We found that half of the quality-of-life instruments identified in our study contained items relating to spirituality. Most of these items were related to meaning or purpose of life and are possibly phrased in such universal terms to develop an item that make sense to all respondents, and not only to people adhering to a belief or religion. A recent study on the conceptualization of measurable aspects of spirituality identified the following dimensions of spirituality as the most important: spiritual beliefs, spiritual activities, and spiritual relationships, and spiritual coping.[14] Spirituality or existential issues can offer patients a way that may help to cope with illness and illness-related difficulties and therefore, conceptualization of spiritual aspects requires further attention. Understanding a patient's quality of life and whether a patient has any spiritual distress can also help to assist caregivers in planning palliative care.

Key findings and interpretation of the results regarding the quality of the instruments

Twenty-nine questionnaires were found to be appropriate to assess the quality of life of palliative care patients. The previous paragraph discussed the content of the instruments and demonstrated that some only included one or two quality-of-life domains. These instruments can be considered as domain-specific measures. We also identified measures that were disease-specific, e.g. specifically developed for cancer patients, setting-specific measures such as those specifically developed for use in a hospice setting, and more generic measures, targeted on palliative care populations in general. The advantage of the more generic measures is that they are suitable for use in patients with different conditions, and they make comparisons across different palliative care populations and settings possible. Domain-specific measures and disease-specific measures are intended to provide more information or more specific information. However, whether more information will be gained by use of a domain-specific instrument is clearly dependent on the measurement properties of the instrument.

The majority of the 29 quality-of-life instruments that were identified had not yet been adequately evaluated with regard to their measurement properties. Consequently, none of them achieved satisfactory ratings for all the measurement properties. This is probably due to the strictness of the criteria we used to assess whether the measurement properties were adequately evaluated and if the instrument showed satisfactory results with regard to the measurement properties. Seven of the 29 questionnaires identified in our review study were revised versions. In other words, researchers tried to improve the original instrument, mostly by excluding the least relevant items, resulting in a shorter questionnaire. Revision can improve the practical feasibility of the instrument but it does not automatically mean that the clinimetric quality has improved.

The number of measurement instruments designed to assess quality of life is rapidly increasing but have not yet been adequately evaluated. Consequently, selecting an instrument has become a big challenge for researchers and clinicians. The choice of a measurement method is a crucial part of research and imperative to the evaluation of outcomes since it determines the quality of data. Apart from the clinimetric quality of the instrument the purpose of measurement also plays a role in the choice. Understanding of the strengths and limitations with regard to the clinimetric quality of an instrument is of crucial importance to the adequate choice of one suiting the purpose of the study. For instance, if the purpose of measurement is evaluation, testing for responsiveness is important, and if the aim of the study is discrimination, reliability testing is of significance. The instrument must fit the measurement goal, but also the feasibility of an instrument is important. Information on the length of the questionnaire, the time needed to complete the questionnaire and the method of administration of a measure varies widely over the instruments, and could also help clinicians and researchers to decide which instruments may be appropriate and/or feasible for a particular study or setting. However, the amount and quality of information gained by the use of one or more instruments should be balanced with the burden they place on the respondents and the costs of data collection. Self-report questionnaires are generally preferred over the use of caregivers or significant others as raters. Inconsistent findings exist with regard to the use of proxy raters while the use of self-report questionnaires refers to assessment directly from the patient which can be considered as the most valid way of collecting subjective data such as that on quality-of-life.[32] However, proxies may be considered an alternative or complementary source of information since patients receiving palliative care are not always able to complete a questionnaire themselves.

Suggestions for research policy and practice regarding quality-of-life measures

Since most of the instruments that were identified had not yet been adequately evaluated it was not possible to provide an explicit recommendation for one specific quality-of-life instrument for use in palliative care. However, it is useful to make researchers and clinicians aware of the state of the art in quality-of-life measures for use in palliative and end-of-life care. A clear overview of the current level of development regarding the availability and appropriateness of the quality-of-life measures for palliative care can help researchers and clinicians to select an instrument. No specific instrument have been shown to be the best to assess quality of life and therefore the use of the instruments that received the best ratings for their measurement properties MQOL, followed by the QUAL-E and the QODD, can be recommended. In addition we would recommend evaluation of existing multi-dimensional instruments with a good content validity over developing new instruments as there already exists a wide variety of instruments intended to assess the construct of quality of life. The use of comprehensive quality-of-life measures could help caregivers to plan palliative care services and to set priorities in order to achieve the best possible quality of life for patients in the last phase of life. Thus, the outcome measures should be comprehensive and reflect the specific goals of palliative care. A first step in selecting a quality-of-life instrument for use in a study in palliative care is to specify the aims of the study or clinical problems of interest and to compare these with the content of the instrument.[32] If quality of life will be measured to evaluate an intervention, it is important to consider in which domains change is expected and to select an instrument that includes these domains. Second, it is important to be aware of how the instrument was developed and the strengths and weaknesses of an instrument to interpret the results adequately.

In accordance with what we described earlier, organisations like the EAPC and IAHPC should take the initiative in mobilising international palliative care organisations to develop a network and infrastructure to share, distribute and integrate knowledge and expertise internationally. Coordinated actions should encourage and foster international collaboration to create international agreement on instruments to measure outcomes for palliative care. In addition, EAPC and IAHPC should guide the coordination to stimulate further development and testing and promotion of the use of one or a few well-developed and adequately tested instruments. Furthermore, the translation of instruments should be coordinated to stimulate appropriate translation in order to enable cross-cultural comparison between studies. Moreover, standardization and repetitive use of measurement instruments creates better understanding of the meaning of scores and changes in scores on a specific instrument, so that the score can be translated into information that is meaningful to the patient, clinician or researcher. An important advantage of the use of one or a few high-quality instruments is the comparability of research results providing more robust evidence to facilitate guideline development, evidence-based care, and policy making. An important recommendation for research funders is that they should create research programmes in the field of palliative care focussing on conceptual, methodological and clinimetric research.

Part III

Measuring dignity at the end of life

While improvement of quality of life has been considered as the main purpose of palliative care, patients frequently speak about the importance of preserving their personal dignity when considering the end of life. As a consequence dignity has been seen as a central goal of palliative care but is still a relatively new concept in research. In line with the growing interest of the concept of personal dignity, measuring dignity in palliative care research has become of significant importance. Especially with regard to studies investigating the patient perspective, dignity can be a very useful outcome in order to provide a comprehensive understanding of the patient's wellbeing. Therefore, our studies make an important contribution to the better understanding of the concept of dignity at the end of life.

Key findings and interpretation of the results regarding measuring dignity

Investigating the construct of personal dignity and the content validity of the Patient Dignity Inventory showed that independence, incontinence, pain, mental clarity, dementia, the ability to communicate and adequate care have important influence on personal dignity at the end of life. The majority of the items in the Patient Dignity Inventory were also found to be relevant to the sense of dignity at the end of life by people with an advance directive; however, the items did not comprehensively reflect the construct of dignity as items on communication and care-related aspects were not included in the instrument. In view of those findings, the way caregivers approach patients and communicate with them can be seen to have great influence on dignity at the end of life. Considering that physical and mental independence which influence a patient's sense of dignity cannot be changed, relatives and caregivers should aim to preserve dignity in a patient's last phase of life. A new measurement instrument was developed in accordance with the findings from our study that evaluated the construct of personal dignity and the content validity of the Patient Dignity Inventory prototype.[33] This instrument can be used to measure the influence as well as the presence of factors that influence self-perceived dignity, and consists of four domains: evaluation of self in relation to others, functional status, mental status, and care and situational aspects.

The results from the study described in Chapter 6 showed that the perceptions of factors maintaining personal dignity at the end of life of people in good health were not substantially different from the perceptions of people who suffer from any disease and/or disability except for three physical factors related to symptoms, roles and routines. Those items were considered significantly more influential on dignity for people with poor health status. This would suggest that healthy people tend to underestimate the physical aspects that were found to be influential on dignity at the end of life. The results also suggest that people do not change their mind about the influence of psychological, social and existential factors on personal dignity at the end of life when their health status changes. Socio-demographic characteristics such as gender, age, having a partner and having a belief or religion rather than health status affect the perception of factors influencing dignity at the end of life. Although patients need to adjust continuously during the illness trajectory to find a way to cope with their changing health condition, the data suggest that the understanding of dignity will not substantially change as health status changes. The understanding of personal dignity and especially the psychological, social and existential factors covered by this construct seem to be reasonably stable. Although several authors[34-36] have expressed concerns about patients who may change their minds about life values and preferences for care when confronted with a serious illness or in an illness trajectory, an important implication followed from the study (Chapter 6) might be that personal dignity can already be discussed in good health or in an early stage of a disease. Discussing a patient's understanding of dignity can be part of advance care planning and help to develop value-based preferences about future care. However, we need to be cautious in suggesting that people's views on dignity remain stable during the trajectory of illness as our study was not a longitudinal research study.

In Chapter 7 we showed that Dutch caregivers involved in caring for dying patients consider the same items as relevant to dignity as terminally ill patients. However, the trained volunteers included in this study indicated these items more frequently as influential to dignity, and as problematic in practice to maintaining dignity at the end of life than did SCEN (Support and Consultation on Euthanasia)-physicians. It seems that SCEN-physicians consider the physical aspects of suffering as most influential and problematic in practice to preserving dignity while volunteers think psychosocial aspects are most important. An explanation might be that volunteers are more often involved in someone's personal life and are listening to what matters to the patient and his or her relatives. SCEN-physicians visit the people who explicitly request euthanasia in order to assess the their suffering and whether it is unbearable.[37] This could explain why SCEN-physicians seem to focus more on physical suffering. A caregiver's role in providing care for a terminally ill patient seems to affect their perception of the influence of factors that could maintain dignity.

Suggestions for research policy and practice regarding measuring dignity

Caregivers play an important role in the provision of care and support for terminally ill patients. With regard to future research, comparison of patient perceptions of dignity at the end of life and the perceptions of their caregivers in one study would be helpful to further explore understanding of and attitudes towards dignity, in particular because caregivers do have an important role in providing care for terminally ill patients, and communication and care-related aspects showed as important factors influencing sense of dignity at the end of life. Therefore, some of the results concerning the perceptions of dignity at the end of life are of particular interest for care providers involved in palliative care. Caregivers should be aware of the impact they may have in preserving dignity. This is in line with two previous studies that stressed the importance of the role of nursing staff in preserving dignity in elderly people.[38, 39] Anderberg et al. described that the concept of preserving dignity should be part of caregivers' thinking in order to provide good care.[38] Dignity should become a subject of education and training, especially for people providing palliative care. In palliative care practice, measuring dignity can be helpful for caregivers to identify which factors affect or have affected a patient's sense of dignity in order to change focus of caregiving. The use of an instrument to measure factors that influence dignity can also be helpful to initiate and facilitate communication about values and preferences for care at the end of life. This can be considered as even more important since a lack of understanding of a patient's wishes about future care might result in loss of dignity, and additional distress for relatives and caregivers. Thus an outcome measure to assess personal dignity may be helpful in the process of advance care planning, to discuss and evaluate patients' preferences for future care, early in the illness trajectory or even before the issues arise due to disease or disabilities. An adequate and appropriate instrument is needed to identify factors that affect or have affected a patient's sense of dignity. Therefore, more research regarding the feasibility and validity of the dignity-instrument we referred to in the previous paragraph 33 would be recommended. It would also be helpful to know whether this instrument can be used as a proxy assessment instrument. Future longitudinal research is needed to investigate whether peoples' views on dignity remains stable during the trajectory of illness to verify or disprove the assumption that personal dignity might be a stable construct. Furthermore, it would be interesting to further explore what additional information would be gathered by measuring dignity in addition to quality of life considering that dignity and quality of life have some overlapping domains.

Conclusions

Much research has been done in the field of palliative care, with a main focus on cancer palliative care. As a growing number of people will be in need of palliative care over the coming years a lot more research is needed with a new focus on palliative care for non-cancer patients and palliative care in long-term care facilities. Research is very important to evaluate present palliative care services and to further develop adequate palliative care. However conceptual clarity and the development of well-defined and more standardized descriptions concerning quality of palliative care are needed to develop high-quality research. In addition, special attention should be paid to the identification of outcomes reflecting the concerns of patients receiving palliative care in these settings, and the development and validation of measurement instruments that can be used for proxy assessments

Quality of life is a central concept and an important outcome measure in palliative care, and therefore measurement instruments to measure quality-of-life are of great importance. Personal dignity is increasingly considered as a goal of palliative care but is a relatively new concept in the field. Comparing the concepts of dignity and quality of life suggests that these concepts include some overlapping domains. Physical, socio-psychological and spiritual aspects are reflected in both concepts. The concept of personal dignity goes beyond the assessment of physical and psychological health status as it also includes one's perception of worthiness. In addition to quality of life, personal dignity might be an important and comprehensive outcome in palliative care research, especially with regard to research on patient perspective in this field.

References

1. Brandt HE, Deliens L, van der Steen JT, Ooms ME, Ribbe MW, van der WG. The last days of life of nursing home patients with and without dementia assessed with the palliative care outcome scale. Palliative Medicine 2005 Jun;19(4):334-42.
2. Borgsteede SD, Deliens L, Francke AL, Stalman WA, Willems DL, van Eijk JT, et al. Defining the patient population: one of the problems for palliative care research. Palliat Med 2006 Mar;20(2):63-8.
3. http://www.cosmin.nl/.
4. Terwee CB, Jansma EP, Riphagen II, de Vet HC. Development of a methodological PubMed search filter for finding studies on measurement properties of measurement instruments. Qual Life Res 2009 Oct;18(8):1115-23.
5. Addington-Hall J.M., Bruera E, Higginson I.J., Payne S. Research Methods in Palliative Care. Oxford University Press; 2009.
6. Bouter L.M., van Dongen M.C.I.M. Epidemiologisch onderzoek Opzet en interpretatie. Houten/Diegem: Bohn Stafleu Van Loghum; 2000.
7. van Wijmen MP, Rurup ML, Pasman HR, Kaspers PJ, Onwuteaka-Philipsen BD. Design of the Advance Directives Cohort: a study of end-of-life decision-making focusing on Advance Directives. BMC Public Health 2010;10:166.
8. Hall S., Petkova P., Tsouros A.D., Costantini M., Higginson I.J. Palliative care for older people: better practices. 2011.
9. George LK. Research design in end-of-life research: state of science. Gerontologist 2002 Oct;42 Spec No 3:86-98.
10. Jordhoy MS, Kaasa S, Fayers P, Ovreness T, Underland G, hlner-Elmqvist M. Challenges in palliative care research; recruitment, attrition and compliance: experience from a randomized controlled trial. Palliat Med 1999 Jul;13(4):299-310.
11. Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. BMJ 2005 Apr 30;330(7498):1007-11.
12. Ribbe MW. Care for the elderly: the role of the nursing home in the Dutch health care system. Int Psychogeriatr 1993;5(2):213-22.
13. Kaasa S, Hjermstad MJ, Loge JH. Methodological and structural challenges in palliative care research: how have we fared in the last decades? Palliat Med 2006 Dec;20(8):727-34.
14. Gijsberts MJ, Echteld MA, van der Steen JT, Muller MT, Otten RH, Ribbe MW, et al. Spirituality at the end of life: conceptualization of measurable aspects-a systematic review. J Palliat Med 2011 Jul;14(7):852-63.
15. Nekolaichuk CL, Bruera E, Spachynski K, MacEachern T, Hanson J, Maguire TO. A comparison of patient and proxy symptom assessments in advanced cancer patients. Palliat Med 1999 Jul;13(4):311-23.
16. Higginson I, Priest P, McCarthy M. Are bereaved family members a valid proxy for a patient's assessment of dying? Soc Sci Med 1994 Feb;38(4):553-7.
17. Kristjanson LJ, Hanson EJ, Balneaves L. Research in palliative care populations: ethical issues. J Palliat Care 1994;10(3):10-5.

18. Houttekier D, Cohen J, Bilsen J, Addington-Hall J, Onwuteaka-Philipsen BD, Deliens L. Place of death of older persons with dementia. A study in five European countries. J Am Geriatr Soc 2010 Apr;58(4):751-6.
19. Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. J Am Geriatr Soc 2005 Feb;53(2):299-305.
20. http://www.who.int/cancer/palliative/definition/en/.
21. Stewart AL, Teno J, Patrick DL, Lynn J. The concept of quality of life of dying persons in the context of health care. J Pain Symptom Manage 1999 Feb;17(2):93-108.
22. Hearn J, Higginson IJ. Outcome measures in palliative care for advanced cancer patients: a review. J Public Health Med 1997 Jun;19(2):193-9.
23. Bausewein C, Daveson B, Benalia H, Simon ST, Higginson IJ. Outcome measurement in palliative care, The essentials. 2011.
24. Osoba D. Lessons learned from measuring health-related quality of life in oncology. J Clin Oncol 1994 Mar;12(3):608-16.
25. Saunders C. A personal therapeutic journey. BMJ 1996 Dec 21;313(7072):1599-601.
26. Byock I. Where do we go from here? A palliative care perspective. Crit Care Med 2006 Nov;34(11 Suppl):S416-S420.
27. Byock IR. To life! Reflections on spirituality, palliative practice, and politics. Am J Hosp Palliat Care 2006 Dec 20;23(6):436-8.
28. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 2000 Nov 15;284(19):2476-82.
29. Steinhauser KE, Voils CI, Clipp EC, Bosworth HB, Christakis NA, Tulsky JA. “Are you at peace?”: one item to probe spiritual concerns at the end of life. Arch Intern Med 2006 Jan 9;166(1):101-5.
30. Thomas J, Retsas A. Transacting self-preservation: a grounded theory of the spiritual dimensions of people with terminal cancer. Int J Nurs Stud 1999 Jun;36(3):191-201.
31. Cohen SR, Mount BM, Tomas JJ, Mount LF. Existential well-being is an important determinant of quality of life. Evidence from the McGill Quality of Life Questionnaire. Cancer 1996 Feb 1;77(3):576-86.
32. Kaasa S, Loge JH. Quality of life in palliative care: principles and practice. Palliat Med 2003 Jan;17(1):11-20.
33. Vlug MG, de Vet HC, Pasman HR, Rurup ML, Onwuteaka-Philipsen BD. The development of an instrument to measure factors that influence self-perceived dignity. J Palliat Med 2011 May;14(5):578-86.
34. Kohut N, Sam M, O’Rourke K, MacFadden DK, Salit I, Singer PA. Stability of treatment preferences: although most preferences do not change, most people change some of their preferences. J Clin Ethics 1997;8(2):124-35.
35. Silverstein MD, Stocking CB, Antel JP, Beckwith J, Roos RP, Siegler M. Amyotrophic lateral sclerosis and life-sustaining therapy: patients’ desires for information, participation in decision making, and life-sustaining therapy. Mayo Clin Proc 1991 Sep;66(9):906-13.
36. Weissman JS, Haas JS, Fowler FJ, Jr., Gatsonis C, Massagli MP, Seage GR, III, et al. The stability of preferences for life-sustaining care among persons with AIDS in the Boston Health Study. Med Decis Making 1999 Jan;19(1):16-26.

37. http://www.euthanasiecommissie.nl/Images/Jaarverslag%202008%20Engels_tcm52-27032.pdf.
38. Anderberg P, Lepp M, Berglund AL, Segesten K. Preserving dignity in caring for older adults: a concept analysis. J Adv Nurs 2007 Sep;59(6):635-43.
39. Jacelon CS, Connelly TW, Brown R, Proulx K, Vo T. A concept analysis of dignity for older adults. J Adv Nurs 2004 Oct;48(1):76-83.

Summary
Samenvatting

Summary

Palliative care is the active, total care for patients and their families who face the problems associated with a disease that is not responsive to curative treatment. The palliative care approach focuses on controlling all aspects of suffering – physical, social, psychosocial and spiritual. The intention is neither to prolong life nor to hasten death but to enhance the quality of life of patients and their families. The ageing population with increasingly more people suffering from chronic diseases means a growing number of people will be in need for palliative care. Palliative care research is of utmost importance in informing policymakers and improving clinical practice. However, many practical and ethical challenges are associated with research in this field, particularly because patients in the last phase of life are rarely stable, are often cognitively impaired and the type of intervention they receive varies. There is a lack of conceptual clarity and wide range of definitions in research on palliative care. Determining appropriate outcomes and identifying measurement instruments for the adequate assessment of outcomes is challenging. Quality of life is the main focus of palliative care and therefore considered as an important outcome measure. Dignity is increasingly considered as a goal of palliative care but is a relatively new concept in this field.

This thesis contains three parts of which the first focuses on research methodology in palliative care research in long-term care facilities. Part II focuses on measuring quality of life in palliative care and part III on personal dignity at the end of life. We hope to contribute to a better understanding of the current state of the art in palliative care research in long-term care facilities as these facilities are becoming more important in the provision of palliative care for older people, and to provide helpful information about measuring the concepts of quality of life and dignity in research in palliative care.

Part I – Research methodology in palliative care research in long-term care facilities

In Chapter 2 the methodological rigour in palliative care research in long-term care facilities in Europe is explored. In order to find all papers reporting on patient outcome data of palliative care populations residing in long-term care facilities in Europe we performed a systematic literature review. Fourteen mainly descriptive studies were found. None described their study population specifically as a palliative care or end-of-life care population, most were conducted in the Netherlands and many different measurement instruments were used, mostly as proxy ratings to measure symptoms and symptom management. To improve future research on palliative care in long-term care facilities, agreement on what can be considered as palliative care in long-term care facilities and the availability of well-developed and tested measurement instruments is needed to provide more evidence, and to make future research more comparable.

Part II - Quality of life as outcome measure in palliative care

Chapter 3 provides an overview of the content and domains measured by the quality-of-life instruments that are appropriate for use in palliative care. First, we performed a non-systematic literature review to identify the domains most important for the quality of life for palliative care patients. A quality-of-life framework was developed including the following domains: physical comfort, physical functioning, cognitive functioning, psychological, social and spiritual wellbeing and perceived quality of life. A second systematic literature review identified 29 instruments suitable for use in palliative care and in measuring quality of life. None of these instruments covered all aforementioned domains but only one or two quality-of-life domains. As spirituality is not well defined but considered as an important issue in palliative care we specifically focused on the domain of spirituality to find out how this domain was operationalized in the instruments. Most of the spiritual items concerned the meaning or purpose of life.

Chapter 4 is also based on the systematic literature review that identified the 29 quality-of-life instruments but this chapter reports the instrument characteristics such as target population, number of items, time needed to complete them etc. In order to assess the clinimetric quality of the instruments we evaluated the measurement properties by use of a widely accepted rating list. None of the instruments demonstrated satisfactory results. As not all measurement properties of all instruments have yet been adequately tested, we have not been able to provide an explicit recommendation for the use of one specific instrument. Overall, the MQOL, followed by the QUAL-E and the QODD, received the best ratings for their measurement properties. The information about practical aspects and clinimetric quality of the instruments can help clinicians and researchers in their choice of an instrument. The evaluation of existing instruments with good content validity should have priority over the development of new instruments.

Part III - Dignity as outcome measure in palliative care

Chapter 5 describes how we analysed the construct of personal dignity in addition to the evaluation of the content validity of the Patient Dignity Inventory. Data for this study were collected within the framework of an advance directives cohort study. One half of the cohort (n=2537) received a questionnaire including the Patient Dignity Inventory whilst the other half of the cohort (n=2404) received a questionnaire including an open-ended question on personal dignity. Content labels were assigned to issues mentioned in the responses to the open-ended question. The COSMIN checklist ('COnsensus-based Standards for the selection of health status Measurement INstruments') was used to assess the relevance and comprehensiveness of the items of the Patient Dignity Inventory. The study demonstrated that the items of the Patient Dignity Inventory were relevant for people with an advance directive, and that in addition to being valid for use in terminally ill cancer patients, the Patient Dignity Inventory can be used in a general population to obtain insight into people's thoughts about what would constitute dignity in the last phase of their life, although the comprehensiveness of the Patient Dignity Inventory can be improved by including items concerning communication and care-related aspects, and specifically phrasing of the items can improve the Patient Dignity Inventory.

Chapter 6 examines whether health status affects the perceptions of factors influencing personal dignity at the end of life, and the relationship between those perceptions and socio-demographic characteristics. In this study a subsample (n=2282) of the advance directives cohort study was used. Three different health status groups (good, moderate and poor) were defined based on the EQ-5D and a question on whether they had an illness. For each health status group we calculated the percentage of respondents who indicated the extent to which the items of the Patient Dignity Inventory would influence their dignity as large or very large. Logistic regression analyses were used to investigate the associations between the perceptions of factors influencing personal dignity and socio-demographics. The percentage of respondents who indicated the factors as having a large/very large influence on dignity at the end of life were not significantly different for the three health status groups, except for three physical items on symptoms, roles and routines. Those items this chapter reports had significantly more influence on dignity for people with a poor health status. Gender, old age, having a partner and having a belief or religion that is important to one's life were associated with the understanding of factors influential to dignity. Health status seems only to affect perceptions of physical factors maintaining dignity at the end of life. This suggests that the understanding of dignity will not substantially change as health status changes and may support starting advance care planning early.

In Chapter 7 the Patient Dignity Inventory was used to investigate and compare the understanding of physicians and volunteers of factors that can influence a patient's perceived dignity, and can make it problematic in practice to preserve their dignity. A written questionnaire including the Patient Dignity Inventory was sent to two groups of caregivers: trained volunteers (n=236) and end-of-life consultants (Support and Consultation on Euthanasia (SCEN)-physicians; n=427). They were asked the extent to which they considered the items as influential on dignity in terminally ill patients, and as problematic in practice in maintaining dignity for patients in the last phase of life. Overall, volunteers more frequently indicated the items of the Patient Dignity Inventory as influential on dignity and problematic in practice to maintain dignity compared with SCEN-physicians. There are some differences in the relative importance of items according to volunteers and SCEN-physicians. It seems that SCEN-physicians consider the physical aspects of suffering as most influential and problematic in practice for preserving dignity while volunteers think psychosocial aspects are most important. This study shows that the role and responsibilities of caregivers involved in the care of terminally ill patients affect the factors that they think influence dignity.

In Chapter 8 the main findings are discussed. Overall, conceptual clarity and the development of well-defined and more standardized descriptions concerning quality of palliative care are needed. In addition, special attention should be paid to the identification of outcomes reflecting the concerns of patients receiving palliative care in these settings, and the development and validation of measurement instruments that can be used for proxy assessment, as many patients receiving palliative care are lacking in capacity and not able to complete self-report questionnaires. Organisations for the promotion and development of palliative care such as the European Association for Palliative Care or the International Association for Hospice & Palliative Care should stimulate and support further development and identification of standardized concepts, definitions and outcomes for palliative care research. These organisations can also help to implement more standardized concepts and outcomes to make research more comparable in order to benefit all researchers in the field.

Research is very important to evaluate present palliative care services and to further develop adequate palliative care. Future palliative care research should not focus solely on cancer patients but also on palliative care for non-cancer patients and those residing in long-term care facilities. In addition to quality of life, personal dignity can be considered as an important outcome measure in palliative care.

Samenvatting

Palliatieve zorg is de zorg voor mensen waarbij genezing niet meer mogelijk is. Het doel van palliatieve zorg is niet om het leven te verlengen of de dood te bespoedigen maar om een zo hoog mogelijke kwaliteit van leven voor patiënten en hun familie en naasten te realiseren. Deze zorg richt zich op het voorkomen en verlichten van lijden om het leven van de patiënt zo comfortabel mogelijk te maken. Palliatieve zorg is een multidisciplinaire benadering en omvat vroegtijdige signalering en zorgvuldige beoordeling en behandeling van pijn en andere problemen van lichamelijke, psychosociale en spirituele aard. Traditioneel gezien richt palliatieve zorg zich op mensen met kanker. Echter is er in de periode voorafgaand aan de terminale fase en in patiëntenpopulaties met niet-oncologische aandoeningen zoals CVA, COPD en hartfalen ook behoefte aan palliatieve zorg.

De vergrijzing en een groeiend aantal mensen dat lijdt aan (meerdere) chronische aandoeningen leidt tot een hogere vraag naar palliatieve zorg. Goed wetenschappelijk onderzoek naar palliatieve zorg is van groot belang voor de ontwikkeling en verbetering van de palliatieve zorg en bij het informeren en adviseren van beleidsmakers in de zorg. De opzet en uitvoering van onderzoek naar palliatieve zorg brengt echter tal van praktische en ethische dilemma's met zich mee. Het selecteren van palliatieve patiënten voor deelname aan een onderzoek is gecompliceerd doordat deze patiënten vaak ernstig ziek zijn, last hebben van cognitieve beperkingen, zelden in een stabiele toestand verkeren en hun zorgbehoeften continu veranderen. Door het gebruik van een breed scala van definities en uitkomstmaten in onderzoek naar de zorg rondom het levenseinde is het soms lastig om onderzoekspopulaties en uitkomsten van onderzoek met elkaar te vergelijken. Zo worden concepten als de terminale fase, stervensfase en het levenseinde op verschillende manieren gebruikt gedefinieerd en geïnterpreteerd, wat leidt tot de nodige verwarring. Om het effect van een behandeling te kunnen meten of de zorg over een bepaalde periode te evalueren is het belangrijk dat een geschikte uitkomstmaat wordt gekozen en is een betrouwbaar en valide meetinstrument nodig. Omdat de kwaliteit van leven centraal staat in palliatieve zorg is het meten van kwaliteit van leven buitengewoon belangrijk. Daarnaast wordt het waardig laten sterven van mensen vaak gezien als het streefdoel van palliatieve zorg.

Dit proefschrift bestaat uit drie delen. Het eerste deel gaat over onderzoeksmethoden in onderzoek naar palliatieve zorg in instellingen voor langdurige zorg. Deel twee van dit proefschrift richt zich op het meten van kwaliteit van leven in de palliatieve zorg en deel drie gaat over persoonlijke waardigheid aan het levenseinde.

Deel I – Onderzoeksmethodologie in onderzoek naar palliatieve zorg in instellingen voor langdurige zorg

Met een groeiend aantal ouderen en chronisch zieken neemt de behoefte van palliatieve zorg in instellingen voor langdurige zorg zoals verpleeghuizen toe. Hoofdstuk 2 beschrijft een systematisch literatuuronderzoek waarin is gezocht naar studies over palliatieve zorg in instellingen voor langdurige zorg. Het doel was inzicht te krijgen in de onderzoeksmethodogie en uitkomstmaten in onderzoek naar palliatieve zorg in instellingen voor langdurige zorg dat uitgevoerd is in Europa. Veertien voornamelijk beschrijvende studies met een prospectief en retrospectief design werden gevonden. Acht studies weren uitgevoerd in Nederland en geen van alle studies beschreef de studiepopulatie expliciet als een palliatieve populatie. Veel verschillende meetinstrumenten werden gebruikt, waarbij vaak proxy-respondenten (familie of zorgverleners) werd gevraagd naar de mate van aanwezigheid van symptomen of het effect van de behandeling van symptomen. Om toekomstig onderzoek naar palliatieve zorg in instellingen voor langdurige zorg te verbeteren is de beschikbaarheid en het gebruik meetinstrumenten die ook speciaal ontwikkeld en getest zijn voor gebruik in deze instellingen van groot belang. Belangrijk is ook dat de zorg in instellingen voor langdurige zorg zoals verpleeghuizen beschouwd wordt als palliatieve zorg.

Deel II – Kwaliteit van leven als uitkomstmaat in de palliatieve zorg

Hoofdstuk 3 geeft een overzicht van de inhoud van vragenlijsten waarmee kwaliteit van leven gemeten kan worden in de palliatieve zorg. Eerst is een verkenning van de literatuur uitgevoerd om te bepalen welke domeinen het meest van belang zijn voor de kwaliteit van leven van mensen met een ongeneeslijke aandoening. Uit de literatuur bleken de volgende domeinen het meest van invloed op de kwaliteit van leven van patiënten zonder (curatieve) behandelmogelijkheden: lichamelijk comfort; (lichamelijk) functioneren; cognitief functioneren; psychisch welbevinden; sociaal welbevinden; spiritueel welbevinden; waargenomen kwaliteit van zorg; algemene kwaliteit van leven.

Een systematisch literatuuronderzoek is uitgevoerd in online gegevensbestanden voor wetenschappelijke literatuur op gebied van geneeskunde (PubMed en Embase), verpleegkunde (CINAHL) en psychologie (PsycINFO). Een zoekstrategie werd opgebouwd uit zoektermen rondom kwaliteit van leven en palliatieve zorg en bevatte een verzameling zoektermen ontworpen om studies over de ontwikkeling en/of validatie van vragenlijsten te vinden. Het systematisch literatuuronderzoek leverde 29 verschillende vragenlijsten op die kwaliteit van leven meten bij patiënten die palliatieve zorg ontvangen. De meeste vragenlijsten bevatten één of twee van alle bovengenoemde domeinen. Omdat spiritualiteit wordt gezien als een belangrijk onderwerp binnen de palliatieve zorg is specifiek aandacht besteed aan de wijze waarop spiritualiteit geoperationaliseerd (meetbaar gemaakt) is in de kwaliteit-van-leven vragenlijsten. Vijftien van de 29 vragenlijsten bevatte één of meer items gerelateerd aan spiritualiteit. Deze items gingen vaak over een doel of betekenis van het leven.

Hoofdstuk 4 beschrijft de praktische toepasbaarheid en klinimetrische kwaliteit van de 29 verschillende vragenlijsten waarmee kwaliteit van leven gemeten kan worden bij patiënten die palliatieve zorg ontvangen. Twee onderzoekers hebben onafhankelijk van elkaar gekeken naar een aantal algemene kenmerken van de vragenlijst, zoals de doelpopulatie, de gemeten domeinen van kwaliteit van leven, het aantal vragen en de invultijd. De klinimetrische kwaliteit werd ook door twee personen onafhankelijk van elkaar beoordeeld met behulp van kwaliteitscriteria. De volgende meeteigenschappen zijn beoordeeld: inhoudsvaliditeit, constructvaliditeit, interne consistentie, reproduceerbaarheid, responsiviteit en interpreteerbaarheid. De klinimetrische kwaliteit bleek sterk te verschillen tussen de vragenlijsten. Voor veel vragenlijsten gold dat de meeteigenschappen niet of niet op de juiste wijze waren geëvalueerd waardoor het niet mogelijk was een aanbeveling te doen voor het gebruik van één bepaalde vragenlijst. De meeteigenschappen van de MQOL en de QUAL-E en QODD werden het best beoordeeld. De informatie over algemene eigenschappen van de vragenlijsten en de klinimetrische kwaliteit bieden samen een hulpmiddel voor het kiezen van een vragenlijst voor klinische toepassingen of onderzoeksdoeleinden. Niet het ontwikkelen van nieuwe vragenlijsten maar het verder testen van meeteigenschappen van bestaande vragenlijsten wordt aanbevolen.

Deel III – Waardigheid als uitkomstmaat in de palliatieve zorg

Waardigheid is een thema dat vaak ter sprake komt in gesprekken rond zorg voor stervende patiënten. Mensen waardig te laten sterven wordt vaak beschouwd als centraal doel van palliatieve zorg. Echter is het concept waardigheid relatief nieuw in onderzoek naar palliatieve zorg en niet eenduidig gedefinieerd waardoor de term op verschillende manieren gebruikt wordt. Op basis van een kwalitatieve studie rondom waardigheid bij terminale kankerpatiënten ontwikkelden de Canadese onderzoeker Chochinov en zijn collega's een model rond waardigheid en een vragenlijst van 22-items om stress gerelateerd aan waardigheid aan het einde van het leven te meten.

Het doel van het onderzoek beschreven in hoofdstuk 5 was: 1) het analyseren van het construct persoonlijke waardigheid aan het levenseinde bij mensen met een wilsverklaring in Nederland, en 2) het evalueren van de inhoudsvaliditeit van de Patient Dignity Inventory. Dit onderzoek werd ingebed in een groot cohortonderzoek onder mensen met een wilsverklaring. Eén helft van het cohort (n=2537) kreeg de vraag om de Patient Dignity Inventory in te vullen en voor ieder item aan te geven in welke mate dit van invloed zou zijn op het gevoel van waardigheid aan het levenseinde. De andere helft van het cohort (n=2404) kreeg een vragenlijst die een open vraag bevatte waarin mensen gevraagd werd wat zij verstaan onder waardigheid aan het levenseinde en welke factoren van invloed zouden zijn op het gevoel van persoonlijke waardigheid wanneer zij ongeneeslijk ziek zouden zijn. De antwoorden op deze open vraag werden geanalyseerd door het labelen van thema's die vaak genoemd werden. Vervolgens werd met behulp van de COSMIN-checklist ('COnsensus-based Standards for the selection of health status Measurement INstruments') de inhoudsvaliditeit van de Patient Dignity Inventory onderzocht. De meerderheid van de items van de Patient Dignity Inventory werd als relevant beschouwd door mensen met een wilsverklaring. Echter bleek uit de antwoorden op de open vraag dat het Patient Dignity Inventory niet het hele concept dekt. Aspecten die gerelateerd zijn aan communicatie en aan zorg ontbraken in de Patient Dignity Inventory. Deze studie heeft aangetoond dat de items van de Patient Dignity Inventory behalve voor terminale kankerpatiënten ook relevant zijn voor een meer algemene populatie, mensen met een wilsverklaring. Echter kan de Patient Dignity Inventory verbeterd worden door items rond communicatie en zorg toe te voegen.

Hoofdstuk 6 beschrijft een studie naar de mate waarin gezondheidstoestand van invloed is op factoren die als belangrijk worden gezien voor het behouden van persoonlijke waardigheid aan het levenseinde en de mate van associatie met sociaal demografische kenmerken. Ook de gegevens voor deze studie zijn verzameld binnen de wilsverklaringen cohortstudie, echter is er in deze studie alleen gebruik gemaakt van het deel van het cohort dat de Patiënt Dignity Inventory ingevuld heeft (n=2282). Op basis van zelf gerapporteerde ziekte of aandoening en een EQ-5D score werd de studiepopulatie verdeeld in drie groepen met een verschillende gezondheidsstatus: goed, gemiddeld en slecht. Voor ieder item van de Patient Dignity Inventory werd voor de groep met een goede, gemiddelde en slechte gezondheidstoestand berekend welk percentage van elke groep dacht dat het item van invloed zou zijn op zijn/haar gevoel van persoonlijke waardigheid aan het levenseinde. Met logistische regressieanalyses werd onderzocht of er een associatie bestond tussen sociaal demografische factoren en het belangrijk vinden van de items van de Patient Dignity Inventory voor persoonlijke waardigheid. Het percentage dat aangaf een item belangrijk te vinden voor het behoud van persoonlijke waardigheid aan het levenseinde bleek voor alle items niet significant verschillend over de gezondheidsgroepen, behalve voor drie items uit het fysieke domein gerelateerd aan symptomen, rollen en routines. Deze items werden significant vaker als belangrijk voor het gevoel van persoonlijke waardigheid beschouwd door mensen met een slechte gezondheidstoestand. Geslacht, leeftijd, een partner en het hebben van een geloof dat als belangrijk werd beschouwd bleken geassocieerd met de mate waarin mensen denken dat bepaalde factoren van invloed zijn op het gevoel van waardigheid aan het levenseinde. Gezondheidstoestand lijkt alleen van invloed te zijn op hoe men denkt over fysieke factoren welke belangrijk zouden kunnen zijn voor het behoud van persoonlijke waardigheid aan het levenseinde. Deze bevindingen doen denken dat het idee over waardigheid van mensen met een wilsverklaring weinig verandert wanneer de gezondheidstoestand verandert en zou kunnen pleiten voor het vroegtijdig bespreekbaar maken van wensen ten aanzien van de zorg rondom het levenseinde.

Hoofdstuk 7 beschrijft hoe twee groepen zorgverleners betrokken bij de zorg voor terminale patiënten persoonlijke waardigheid aan het levenseinde beschouwen en welke factoren zij zien als problematisch voor het behoud van waardigheid in de praktijk. Twee groepen zorgverleners werd gevraagd de Patient Dignity Inventory in te vullen: getrainde vrijwilligers (n=236) en SCEN (Steun en Consultatie bij Euthanasie) artsen (n=427). Beide groepen werd gevraagd in hoeverre zij de items van de Patient Dignity Invenotry van invloed vonden op de persoonlijke waardigheid van terminale patiënten en in hoeverre deze items in de praktijk problematisch zijn voor het behouden van een gevoel van persoonlijke waardigheid. In vergelijking met SCEN-artsen vonden vrijwilligers vaker dat de items van de Patient Dignity Inventory van invloed zijn op waardigheid en in de praktijk problematisch voor het behouden van waardigheid. SCEN-artsen gaven het vaakst aan dat fysieke aspecten van lijden van invloed zijn op het gevoel van waardigheid en in de praktijk als problematisch voor het behouden van waardigheid. Vrijwilligers gaven het meest vaak aan dat psychosociale aspecten van invloed zijn op het behoud van waardigheid aan het levenseinde. Deze studie lijkt te laten zien dat de rol en verantwoordelijkheden van zorgverleners betrokken bij de zorg voor ernstig zieke patiënten invloed heeft op het belang dat zij toekennen aan bepaalde factoren die belangrijk zouden kunnen zijn voor het behouden van een gevoel van persoonlijke waardigheid aan het levenseinde.

In hoofdstuk 8 worden de belangrijkste bevindingen en de interpretatie van deze bevindingen besproken. Het gebruik van meer eenduidige en gestandaardiseerde concepten en uitkomstmaten is belangrijk voor het doen van onderzoek in de palliatieve zorg. Goede en betrouwbare meetinstrumenten ontwikkeld en getest in settings waar patiënten palliatieve zorg ontvangen zijn buitengewoon belangrijk om goed onderzoek te kunnen doen. Om de palliatieve zorg te verbeteren en onderzoek naar palliatieve zorg verder te ontwikkelen zou het gebruik van gevalideerde vragenlijsten voor het meten van belangrijke uitkomstmaten in de palliatieve zorg, zoals kwaliteit van leven en waardigheid, gestimuleerd moeten worden. Voor het coördineren van klinimetrisch onderzoek en instrumentontwikkeling is internationale afstemming nodig. De European Association for Palliative Care (EAPC) zou via haar onderzoeksnetwerk samenwerking, ontwikkeling en gebruik van instrumenten kunnen stimuleren en ondersteunen. Ook nationale organisaties zouden zich bij deze en/of dergelijke organisaties aan moeten sluiten om zo bij te dragen aan het implementeren van gestandaardiseerde concepten en uitkomstmaten en het gebruik van betrouwbare meetinstrumenten. Onderzoek uit verschillende landen wordt hierdoor meer vergelijkbaar.

Onderzoek is bijzonder belangrijk om de palliatieve zorg te kunnen evalueren en om aanbevelingen te kunnen doen ter verbetering van de zorg voor patiënten zonder curatieve behandelingmogelijkheden. Verder onderzoek in dit veld zou zich behalve op kankerpatiënten meer moeten focussen op niet-kankerpatiënten en palliatieve zorg voor patiënten in langdurige zorginstellingen. Kwaliteit van leven en persoonlijke waardigheid kunnen worden beschouwd als belangrijke en waardevolle uitkomstmaten in onderzoek naar palliatieve zorg.

List of publications

Articles in international peer-reviewed journals

- Albers G, Pasman HRW, de Vet HCW, Deliens L, Onwuteaka-Philipsen. Does health status affect perceptions of factors influencing dignity at the end of life? [Accepted for publication in J Pain Symptom Manage]
- Gomes B, Higginson IJ, Calanzani N, Cohen J, Deliens L, Daveson BA, et al. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. Ann Oncol 2012 Feb 16.
- Albers G, Harding R, Pasman HRW, Onwuteaka-Philipsen BD, Hall S, Toscani F, et al. What is the methodological rigour of palliative care research in long-term care facilities in Europe? A systematic review. Palliat Med 2012;26(5): 722 - 733.
- Albers G, Pasman HRW, Rurup ML, de Vet HCW, Onwuteaka-Philipsen BD. Analysis of the construct of dignity and content validity of the patient dignity inventory. Health Qual Life Outcomes 2011;9:45.
- Albers G, Echteld MA, de Vet HCW, Onwuteaka-Philipsen BD, van der Linden MHM, Deliens L. Content and spiritual items of quality-of-life instruments appropriate for use in palliative care: a review. J Pain Symptom Manage 2010 Aug;40(2):290-300.
- Albers G, Echteld MA, de Vet HCW, Onwuteaka-Philipsen BD, van der Linden MHM, Deliens L. Evaluation of quality-of-life measures for use in palliative care: a systematic review. Palliat Med 2010 Jan;24(1):17-37.
- Van der Steen JT, Albers G, Licht-Strunk E, Muller MT, Ribbe MW. A validated risk score to estimate mortality risk in patients with dementia and pneumonia: barriers to clinical impact. Int Psychogeriatr 2011 Feb;23(1):31-43.

Other publications

- Francke AL, Albers G, de Veer, AJE, Onwuteaka-Philipsen BD. Panel V&V: Nog steeds veel behoefte aan extra scholing levenseindezorg. TVZ: Tijdschrift voor Verpleegkundigen, 2012;122(2).
- de Veer AJE, Francke AL, Albers G, Onwuteaka-Philipsen BD. SCEN v&v: telefonisch advies bij euthanasie. TVZ:Tijdschrift voor Verpleegkundigen 2011;121(6):41-4.
- Albers G, Echteld MA, de Vet HCW, Onwuteaka-Philipsen BD, van der Linden MHM, Deliens L. Kenmerken en klinimetrische kwaliteit van meetinstrumenten voor de palliatieve zorg: een systematische review. Nederlands-Vlaams Tijdschrift voor Palliatieve Zorg 2011;4.
- van der Steen JT, Albers G, Licht-Strunk E, Muller MT, Ribbe MW. Een prognostische score voor patienten met pneumonie en dementie. Tijdschrift voor Verpleeghuis Geneeskunde 2009;34(2):70-3.
- Onwuteaka-Philipsen BD, Albers G, Cartwright C, Williams G, Faisst K, Mortier F, et al. Wat bespreken artsen met hun patiënten in de terminale fase? Een crossnationale vergelijking. Nederlands Tijdschrift voor Palliatieve Zorg 2008 Jun;9:12-20.

Dankwoord

Dit moment leek altijd zo ver weg maar het is af! Het was een proces en tegelijkertijd een plezierige, stimulerende en leerzame tijd, waarin veel verschillende mensen in verschillende fases belangrijk zijn geweest. Terugkijkend op de periode waarin dit proefschrift tot stand is gekomen ben ik allen die hiertoe hebben bijgedragen dankbaar voor hun inzet, vertrouwen, steun en afleiding. Een aantal mensen wil ik in het bijzonder noemen.

Allereerst wil ik Bregje bedanken voor het mogelijk maken van het gevarieerde onderzoekstraject dat ik heb mogen afleggen. Het was fijn dat ik altijd bij je binnen kon lopen en met jouw reactie op mijn vragen en stukken direct weer aan de slag kon. Veel dank voor jouw begeleiding en vertrouwen.

Ook veel dank aan mijn co-promotor Roeline, voor jouw begeleiding en toegankelijkheid en de fijne samenwerking.

Luc, jouw wetenschappelijke bijdragen en inhoudelijke expertise en ervaring waren altijd waardevol en inspirerend. Ik kijk uit naar onze verdere samenwerking in Brussel.

Riekie, je begeleidde mij tijdens mijn eerste stappen in de wetenschappelijke wereld, mijn bachelor-stageonderzoek en nu ben je mijn derde promotor. Samenwerken met jou heb ik als heel leerzaam en motiverend ervaren. Bedankt voor je inzet en belangstelling.

Verder wil ik alle mensen bedanken die betrokken zijn geweest bij de verschillende projecten waarop dit proefschrift is gebaseerd. Michael dank voor de betrokken begeleiding en goede samenwerking tijdens het meetinstrumentenproject. Mecheline bedankt voor jouw bijdragen aan dit project. Richard thank you for giving me the opportunity to visit the Cicely Saunders Institute in London for 3 months and thanks for your support writing the review paper. The other co-authors of the PRISMA-paper, Miel, Sue and Franco, thank you for your contribution to the article.

De leden van de leescommissie, prof. dr. Anneke Francke, prof. dr. Cees Hertogh, prof. dr. Lieve Van den Block, prof. dr. Agnes van der Heide, prof. dr. Martin Taphoorn, wil ik bedanken voor de tijd en aandacht die zij aan dit proefschrift hebben willen besteden.

Het was fijn om zoveel leuke collega's om me heen te hebben de afgelopen jaren. Ik wil jullie bedanken voor de fijne werkomgeving, jullie belangstelling, meedenken, adviezen, steun en gezelligheid. Berniek, Janneke, Linda, Mariska, Susanne, Ria, Natalie, Matthijs, Pam, Annicka, Isis, Eva, Maaike, Martijn, Hanny, Mette, Ebun en Hilde, en Wieneke, Diana, Liesbeth, Miranda en ook Trees en Inge.

Lieve familie en vrienden, jullie hebben niet direct bijgedragen aan het tot stand komen van dit boekje maar zijn altijd heel belangrijk voor mij. Dank voor alle aandacht, belangstelling, en gezelligheid.

Lieve papa en mama, jullie hebben mij altijd de ruimte gegeven mijn eigen keuzes te maken. Steun en vertrouwen hebben jullie gegeven door er altijd - op de achtergrond - te zijn. Natuurlijk ook mijn lieve zusjes, Pauline en Ileen, wat is het fijn om jullie beide zo dichtbij me te hebben staan. Bedankt dat jullie er altijd zijn en bedankt voor een altijd warm en liefdevol thuisgevoel.

Lieve Maarten, dank je wel voor jouw steun en afleiding de afgelopen tijd en de tijd die je hebt willen investeren in mijn boekje. Ik ben heel blij met mijn kaft!

Lieve Iris en Sophia, mijn paranimfen, onze vriendschap is eigenlijk als een rode draad door mijn leven. Sinds het begin van de basisschooltijd delen wij ontwikkelingen en ervaringen. Ik ben ontzettend blij dat jullie ook nu naast mij staan.

Measuring **quality of life and dignity** in palliative care research

Gwenda Albers was born on November 18, 1983, in Heemskerk, the Netherlands. She completed pre-university education at the Huizermaat in Huizen in 2002. In September 2003 she started studying Health Sciences at the VU University in Amsterdam. She conducted her Master's thesis research with the End-of-Life Research Group at the EMGO Institute for Health and Care Research of the VU University Medical Center (VUmc) Amsterdam. In 2007 she completed her Masters in Policy and Organization of Health Care. In January 2008 she started working as a junior researcher at the EMGO Institute for Health and Care Research of the VUmc Amsterdam where she was involved in palliative care research. She has been working on several projects on quality-of-life measures for use in palliative care, personal dignity at the end of life, a risk score to estimate mortality risk in dementia patients and, the EU (Fp7) supported PRISMA project that was aiming to develop a European collaborative and research agenda on palliative care in long-term care facilities. As part of this latter project she had the opportunity to work as a visiting researcher at King's College Cicely Saunders Institute in London for 3 months. Gwenda is currently working on a project about nurses' attitudes to end-of-life decisions, and on the evaluation of the pilot project 'Support and Consultation on Euthanasia in the Netherlands (SCEN) for nurses'. This project is in collaboration with NIVEL (Netherlands Institute of Health Services Research) where she worked for 5 months in 2011. After obtaining her PhD she will further develop her scientific skills as an 'experienced researcher' in the Marie Curie Initial Training Networks project EURO IMPACT (European Intersectorial and Multi-disciplinary Palliative Care Research Training) at the Vrije Universiteit Brussel.