

Spiritual care at the end of life in Dutch nursing homes

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VRIJE UNIVERSITEIT

Spiritual care at the end of life in Dutch nursing homes

A mixed method study

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Contents

1	General Introduction	7
Systematic review		
2	Spirituality at the End of Life: Conceptualization of Measurable Aspects – A Systematic Review.	19
Qualitative research		
3	Spiritual End-of-life Care in Nursing Homes: An Exploratory Study among Physicians.	41
4	Spiritual end-of-life care in Dutch nursing homes: An ethnographic study.	59
Quantitative research		
5	End-of-life with dementia in Dutch antroposophic and traditional nursing homes, A pilot study.	77
6	When do patients with dementia receive spiritual care at the end of life? A prospective study on predictors of the provision of spiritual end-of-life care as perceived by physicians.	91
7	Perceptions of spirituality and spiritual caregiving at the end of life in elderly care physicians practicing in long-term care: A nationwide survey in the Netherlands.	123
8	General Discussion	139
	Summary	155
	Samenvatting	163
	Dankwoord	173
	About the author	179
	List of publications	180

De moeder het water

Ik ging naar moeder om haar terug te zien
Ik zag een vreemde vrouw. Haar blik was wijd en
leeg, als keek zij naar de verre overzijde
van een water, niet naar mij. Ik dacht: misschien

– toen ik daar stond op het gazon, pilsje gedronken
in de kantine van het verpleegtehuis, de tijd
ging langzaam in die godvergeten eenzaamheid –
misschien zou 't goed zijn als nu Psalmen klonken.

Het was mijn moeder, het lijfje dat daar roer-
loos stond in 't gras, alleen haar dunne haren
bewogen nog een beetje in de wind, als voer

zij over stille waatren naar een oneindig daar en
later, haar God. Er is geen God, maar ik bezwoer
Hem Zijn belofte na te komen, haar te bewaren.

Rutger Kopland

Uit: *Tot het ons loslaat*
Amsterdam, Van Oorschot, 1997

Chapter 1

GENERAL INTRODUCTION

A recent international study in over 21 countries shows that almost a fifth of all deaths in older people occur in nursing homes,¹ in the UK, Belgium and the Netherlands this concerns about a quarter of all deaths,^{2, 3}. The landscape of caregiving at the end of life in the Netherlands is changing. The intention of this transformation of the care system is to allow people to live in their own house as long as possible. From January 2015, the current AWBZ care (Act on Exceptional Medical Expenses) for elderly with physical and mental disabilities will cease to exist. For people that need long term permanent care, the new WLZ (Law on Long term Care) will be applicable, and this care will mostly be institutional care.⁴ Consequently, care in nursing homes will be more complex, and palliative care, including spiritual care, at the end of life will even become more important in Dutch nursing homes than it already is.⁵ Therefore, for many people the nursing home will remain the place where they receive care at the end of life, and their place of death. They are entitled to good care at the end of life, including spiritual care. Spirituality however is a difficult concept, which is a hindrance to assessing spiritual needs and providing care at the end of life that focusses on spiritual needs of nursing home residents.

This thesis aims to contribute to the understanding of the concept of spirituality at the end of life, and to explore current spiritual caregiving to nursing home residents. Specifically, the thesis focuses on the role of elderly care physicians in spiritual caregiving in Dutch nursing homes, including their perceptions and experiences concerning this role.

In this chapter a historical overview will be presented of the development of palliative care and the introduction of the spiritual dimension in palliative care. Further, the concept of spirituality and spirituality at the end of life is introduced. Then, the role of the elderly care physician in spiritual caregiving in Dutch nursing homes is described. Also, the challenges of spirituality and spiritual care in dementia are presented, and the possible role of the physician in spiritual caregiving in Dutch nursing homes. Finally, the research questions of this thesis are presented and the studies we performed to answer the questions are described.

Palliative care and the dimension of spiritual care: a brief history

Palliative care is rooted in and developed from the pioneering work of Dame Cicely Saunders.⁶ She dedicated her work to patients in the terminal stage of illness.⁷ She founded the first modern hospice, the St Christopher's Hospice in London. In her first articles she already showed a wide interest in the needs of her patients, from cancer pain to mental distress,^{8,9} and their interrelationship. The first worldwide focus in palliative care was on the relief of cancer pain. Collaboration between experts in oncology and palliative care resulted in the first World Health Organization paper on palliative care: Cancer Pain Relief.¹⁰ It provided "a guide to pain relief, and the book also serves to put cancer pain in context, describing its nature and extent, reasons for inadequate control, and means by which the problem may be overcome". Although pain relief was the main focus, attention to the wider context was also introduced. In 1988, Cicely Saunders published an article in the Journal of Palliative Care entitled Spiritual Pain.¹¹ She started to develop the concept of total pain, describing that in the individual patient "symptom control is required, . . . , together with an ability to make sense of the inner concerns and values of the person". She also sketched the contours of spirituality and spiritual care at the end of life, as "the need to engage with the whole area of thought concerning moral values". Spiritual pain was described as: "where a desolate sense of meaninglessness is encountered by a person at the end of life". In 1990 the Report on Cancer Pain Relief and Palliative Care was published by the World Health Organization. Two new topics were introduced: first, the dimensions of palliative care, described as "pain and other physical symptoms, the psychosocial needs of the patient and family, and the need for spiritual comfort". Second, the importance of multidisciplinary teamwork is introduced: "The concept of palliative care is explained in terms of its concern with quality of life and comfort before death, emphasis on the family as the unit of care, dependence on teamwork, and relationship to curative interventions".¹² In 1998 the World Health Organization expanded the concept of palliative care to other diseases than cancer and published the paper: Symptom relief in terminal illness, focussing on "the management of secondary symptoms commonly seen in patients suffering from advanced cancer, AIDS, and other terminal diseases". Patient-centred care was introduced: "Emphasis is placed on the need for individual treatment plans that take into account psychological, social, and spiritual aspects as well as physical problems".¹³ The current definition of palliative care by the World Health Organization dates from 2002 "Palliative care is 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".¹⁴

Although the spiritual dimension has been one of the dimensions of palliative care for more than a decade, it is still the least developed one,¹⁵ and it is still marginally represented in textbooks on palliative care. A few examples: in the Oxford Textbook of Palliative Medicine¹⁶ the subject comprises only six pages out of 1244. The first Dutch Guidelines in Palliative Care¹⁷ did not have a chapter on Spiritual Care, but a chapter on Existential Crisis, 18 pages out of 744. The Second Dutch Guidelines¹⁸ has a chapter on spiritual care, written by a theologian, a spiritual care giver, a psychologist, an ethicist and a nurse, comprising 24 pages out of 840.

A systematic review showed that only 6.3% of the studies in 5 palliative care journals between 1994 and 1998 included spiritual or religious variables, and only 1% in leading medical journals.¹⁹ A thematic review of the spirituality literature within palliative care showed 'a prolific increase' of publications on the topic: from 1151 between 1960 and 1969 to 5928 between 2000 and 2005.²⁰ Studies have shown that spiritual care at the end of life is important, because it can contribute significantly to quality of life, the most important outcome measure in palliative care.^{21,22} In a Dutch study on palliative care consultation, most new consultations refer to psychosocial and spiritual needs.²³ The European Association for Palliative Care instituted a taskforce spiritual care in 2010, to promote recognition, research, education, implementation of spiritual caregiving at the end of life.²⁴ In sum: during the last decades there has been an increasing awareness of the importance of spiritual care at the end of life, resulting in the including of spiritual care as a dimension of palliative care, and in an increasing interest in research and the importance of spiritual caregiving at the end of life.

Defining spirituality and spirituality at the end of life

What is spirituality and what is spirituality at the end of life? Spirituality is difficult to define and is variably understood²⁵. A review restricted to the health literature counted 92 separate definitions.²⁰ In health care, nurses have the most frequent and intimate contact with patients, and many articles on spirituality in health care have been published in the nursing literature. Two definitions of spirituality published in nursing journals: "that most human of experiences that seeks to transcend self and find meaning and purpose through connection with others, nature and/or a Supreme Being, which may or may not involve religious structures or traditions" and: "that which gives meaning to one's life and draws one to transcend oneself. Spirituality is a broader concept than religion; religion is one expression of spirituality. Other expressions include prayer, meditation, interactions with others or nature, and relationship with God or a higher power."^{26,27} Three US physicians committed to spirituality in healthcare defined spirituality as "...the search for transcendent meaning – can be expressed in religious practice" or ... "expressed exclusively in their relationship to nature, music, the arts, a set of philosophical beliefs, or relationships with friends and family".²⁸

Since the spiritual dimension is included in the definition of palliative care, spirituality at the end of life has been a focus of interest, internationally as well as in the Netherlands. An article by palliative care researchers from the UK defined spirituality as: "the search for existential or ultimate meaning within a life experience, such as illness. (This belief usually refers to a power other than the self, which people may or may not describe as God, higher power, or forces within nature, and with which they communicate. The power helps the person to transcend the here and now, re-establish hope and the ability to cope)".²⁹ In this article several 'key words' are described that are often mentioned in conceptualizations of spirituality in textbooks and journals: meaning, existential, value, transcendence, connecting, becoming, coping, religion and philosophical. An important publication was the result of a consensus conference in the US in 2009 on improving the quality of spiritual care as a dimension of palliative care, in which experts with different backgrounds (physicians, nurses, spiritual counsellors, and researchers) achieved consensus on a definition of spirituality and recommendations on assessing spiritual needs and providing spiritual care.¹⁵

They defined spirituality as: “the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred”. In the Netherlands, the book on Guidelines in Palliative Care includes a guideline on spiritual care: the Dutch Guideline Spiritual Care in Palliative care.³⁰ The introduction of the guideline states that, when literally translated in Dutch, spirituality is often experienced as an awkward term, that may be associated with (Roman Catholic) rituals, a (protestant) life of personal devotion and faith, but also with new age movements and Eastern philosophies. In the guideline spirituality is described as: “the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred”. In the guideline, spirituality is described as multidimensional, and the following dimensions are distinguished: 1- existential challenges (e.g. questions concerning identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy) 2- Value based considerations and attitudes (what is most important for each person, such as relations to oneself, family, friends, work, things, nature, art and culture, ethics and morals, and life itself), 3- Religious considerations and foundations (faith, beliefs and practices, the relationship with God or the ultimate).

As another study showed that the defining of the concept of spirituality is affected by the particular discipline that is discussing the topic,²⁰ reaching ‘common ground’ on the definition of spirituality at the end of life will not be easy. Therefore, to bridge the different perspectives from different disciplines, it may be helpful to identify dimensions of spirituality at the end of life to obtain more ‘common ground’ between different disciplines, e.g. researchers, physicians, nurses and spiritual counsellors.

In sum, in the different definitions of spirituality and spirituality in the context of palliative care similar keywords may be recognized, e.g. meaning, purpose, connectedness and religious aspects. Spirituality has been described as multi-dimensional and as a dimension of human life.

Spirituality at the end of life in Dutch nursing homes and the role of elderly care physicians

In the Netherlands, medical care in nursing homes is mostly provided by on-staff elderly care physicians.³¹⁻³² These elderly care physicians (formerly called nursing home physicians) have had a three-year vocational training.³³ They are involved in end-of-life care for the more than 32.000 nursing home residents dying on a yearly basis.³² This means the elderly care physician on average provides end-of-life care to more than 20 residents each year. In addition to the direct medical care, the physician is in most cases responsible for the content of the resident’s care plan, in which all the needs, including spiritual needs should be represented, as well as the way and by whom they are addressed. This implies that the physician has a key role in the caregiving by a multidisciplinary team. In long-term care settings, the provision of spiritual care has been associated with families’ perception of better overall care in the last month of life.³⁴

Many studies originate from Northern America. Physicians are relatively unfamiliar with recognising and addressing questions concerning spirituality, although patients pose these questions.³⁴ The importance of spiritual care by physicians has been recognized more and more during the last decades, including spiritual care at the end of life.^{30,36} They show that the extent to which physicians recognize spiritual needs in their patients and acknowledge that spiritual care is also their concern, is strongly related to the way they experience spirituality, religion and the extent to which they practice their religion.³⁷

Most physicians do not ask a patient about religion or spirituality until the patient is dying.³⁸ Lack of time and lack of training are mentioned as barriers.³⁷ Spiritual questions are often not recognized and the addressing of spiritual needs is often not considered as the physicians’ responsibility.³⁹ It is unclear if studies regarding spirituality and spiritual care in American physicians can be extrapolated to the Dutch situation, as the United States is a religious country and most citizens are church members, whereas the Netherlands is a typical West-European secularized country.⁴⁰

Spirituality at the end of life in Dementia

Could spirituality also be important for older people suffering from dementia? An important question, as a quarter (25%) of people aged 85 years and older die with dementia.^{41,42} In the Netherlands, about 11,5% of all deaths concern people with dementia.⁴⁰ A systematic review showed a prevalence of 58% of residents with dementia in long term care settings.⁴³

Spirituality in dementia is still an understudied topic.^{44,45} In the WHO booklet ‘Palliative Care for Older People, better practices’, dementia is considered to be a life-limiting disease, and “patients may therefore have palliative care needs at any point in the illness trajectory and not just the terminal phase”. Spirituality (one of the dimension of palliative care) and spiritual caregiving however are not mentioned.⁴⁶ In ‘Dying with dementia: what we know after more than a decade of research’, van der Steen⁴⁷ concludes that “spiritual care and nursing measures may be less developed than medical care”. A booklet to inform families of patients with advanced dementia on comfort care in several countries did not include spiritual issues.⁴⁶ In ‘Supportive Care for the Person with Dementia’ spiritual issues are described as: ‘acknowledging and supporting spirituality, regard to overall quality of life and promoting dignity. These include support for grieving, the importance of communication, and issues of maintaining the self’.⁴⁹ Recently, the EAPC white paper on palliative care in dementia was published,⁴⁴ an evidence and consensus based Delphi study in which 61 % of the participants were physicians. In the rating of domains being important to palliative care in dementia, the rating of psychosocial and spiritual issues was 7 out of 11 (with small differences in rating between the domains). Also, ‘psychosocial and spiritual support’ had the second to last overall research priority rating. One of the recommendations was that “spiritual caregiving in dementia should include at least assessment of religious affiliation and involvement, sources of support and spiritual wellbeing, and referral to experienced spiritual counsellors such as those working in nursing homes may be appropriate”. Also, “religious activities, such as rituals, songs, and services may help the patient because these may be recognized even in severe dementia”. It is unclear if and how Dutch nursing home residents with dementia receive spiritual care at the end of life, and if facilitators can be identified for the provision of spiritual care at the end of life in Dutch nursing home residents with dementia.

OBJECTIVES AND RESEARCH QUESTIONS OF THIS THESIS

This thesis aims to contribute to the understanding of the concept of spirituality at the end of life and its dimensions, to explore the perception of elderly care physicians of spirituality at the end of life and of their role in spiritual caregiving at the end of life in nursing homes, to explore current spiritual caregiving practices in Dutch nursing homes, and to identify facilitators for spiritual caregiving in Dutch nursing home residents suffering from dementia.

The accompanying research questions for this thesis are:

1. How can spirituality at the end of life be understood?
2. What is the perception of Dutch elderly care physicians of spirituality and their role in spiritual caregiving at the end of life in nursing homes?
3. What spiritual end-of-life care is provided to Dutch nursing homes residents, including residents suffering from dementia?
4. Which facilitators can be identified for spiritual caregiving in Dutch nursing home residents suffering from dementia?

MIXED METHOD RESEARCH DESIGN

As the research questions differ in nature, a variety of qualitative and quantitative research methods were used.

1. To answer the first research question, a **systematic review** on ‘Spirituality at the end-of-life’ was performed. A systematic review provides an overview of information on ‘spirituality at the end of life’, as it locates, appraises and synthesises the evidence from individual studies relevant to the research question and is conducted according to explicit and reproducible methodology.⁵⁰ The systematic review is presented in chapter 2.
2. To answer the second research question, we performed a **focus group study** among elderly care physicians to explore how they perceive spirituality and their role in spiritual caregiving at the end of life in nursing homes. We included a focus group study, because this qualitative research method allows for exploring this understudied and poorly understood topic in a relatively short period of time, and to study and clarify these topics through interaction between the participants.⁵¹ The focus group study is presented in chapter 3 of this thesis.

To study if these results could be generalized, items on spirituality and the role of the physician in spiritual caregiving were also represented in a nationwide **survey** in a representative sample of elderly care physicians. The results show how frequently Dutch elderly care physicians provide spiritual care at the end of life, and the degree to which their perception of spirituality at the end of life corresponds with items of validated instruments that measure spirituality at the end of life. Furthermore, we

explore whether physician’s perception of spirituality relates to their provision of spiritual end-of-life care. The survey is presented in chapter 7 of this thesis.

3. To answer the third research question, an **ethnographic study** was performed to observe the actual practice of spiritual care at the end of life on two wards in a Dutch nursing home: one ward with residents suffering from dementia, and one with residents suffering from physical disabilities. In this qualitative research method, behaviour of and interactions between participants are studied in their natural environment, thus increasing the validity of the data.⁵¹ An ethnographic study also offers the possibility of uncovering behaviour and interactions of which the participants are unaware,⁵² and provides rich, holistic insights into views and actions, through triangulation of data collection, e.g. the collection of detailed observations, information from care plans, medical charts, and interviews.⁵³ The study is presented in chapter 4 of this thesis.
4. To answer the fourth research question, data from two quantitative studies were analysed. The first is a **retrospective study**, in which end of life care (including spiritual aspects) in anthroposophic and traditional nursing homes to residents suffering from dementia was compared, using the ‘End-of-Life in Dementia scales’ (EOLD). This study is presented in chapter 5 of this thesis. The second study, presented in chapter 6 of this thesis, is the **prospective Dutch End of Life in Dementia (DEOLD) study**, in which independent predictors for the providing of spiritual end-of-life care in dementia were identified.

OUTLINE OF THE THESIS

The following six chapters of this thesis, chapter 2 to 7, are based on articles that have been published or submitted to a peer-reviewed scientific journal.

Systematic review

Chapter 2 describes the results of a systematic review on ‘Spirituality at the end-of-life’, in which we aimed to identify dimensions of spirituality at the end of life, based on an analysis of items of instruments that measure spirituality in end-of-life populations.

Qualitative research

Chapter 3 describes the results of a focus group study with elderly care physicians, in which the physicians discuss their perception of spirituality and of spiritual end-of-life care, and their role in spiritual end-of-life care.

Chapter 4 describes the results of an ethnographic study in a nursing home, in which the provision of spiritual care at the end of life to residents with physical disabilities or with dementia was studied, as well as the collaboration and communication between the different professionals on this spiritual end-of-life caregiving, with an emphasis on the role of the elderly care physician.

Quantitative research

Chapter 5 describes the results of a retrospective study, in which we compared end of life care (including spiritual aspects) in anthroposophic and traditional nursing homes to residents suffering from dementia, using the “End-of-Life in Dementia scales”.

Chapter 6 describes results from the prospective Dutch End of Life in Dementia study, in which we identified independent facilitators of the provision of spiritual end-of-life care in dementia.

Chapter 7 describes the results of a survey with elderly care physicians, in which their perception of spirituality at the end of life, their provision spiritual care at the end of life, and the relation between the physician’s perception of spirituality at the end of life and the provision of spiritual end-of-life care was studied.

General Discussion

Chapter 8, the general discussion, summarizes the key findings of the chapters 2 to 7, followed by an interpretation and discussion of the results and presents recommendations for practice, policy and further research on spiritual care at the end of life in nursing homes.

References

1. Broad JB, Gott M, Kim H, Boyd M, Chen H, Connolly MJ. Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *Int J Public Health* 2013; 2:257-67.
2. van der Velden LE, Francke AL, Hingstman L, Willems DL. Dying from cancer or other chronic diseases in the Netherlands: ten-year trends derived from death certificate data. *BMC Palliat Care* 2009 Feb 4;8:4.
3. Houttekier D, Cohen J, Peppersack T, Deliëns L. Dying in hospital: a study of incidence and factors related to hospital death using death certificate data. *Eur J Public Health* 2014 Oct;24(5):751-6
4. Changes in Dutch health care: <http://www.access-nl.org/about-access/news-and-events/news/changes-in-dutch-healthcare.aspx> (last accessed December 2014)
5. WLZ (Law on Long term Care): https://www.ser.nl/-/media/db.../b26705_3 (last accessed September 2015)
6. Saunders C. *The management of patients in the terminal stage*. In: Raven R, ed. Cancer, vol 6. London: Butterworth and Company, 1960. 403–17.
7. Clark D. From margins to centre: a review of the history of palliative care in cancer. *Lancet Oncol* 2007 May;8(5):430-8.
8. Saunders, C. Care of the dying 3. Control of pain in terminal cancer. *Nursing Times* 1959c; October 23:1031-32
9. Saunders, C. Care of the dying 4. Mental distress in the dying. *Nursing Times* 1959d; October 30:1067-69
10. WHO 1986: Cancer Pain Relief: <http://www.whocancerpain.wisc.edu/?q=node/169> (last accessed September 2015)
11. Saunders C. Spiritual pain. *J Palliat Care* 1988 Sep;4(3):29-32
12. WHO 1990: Cancer Pain Relief and Palliative Care, Report of a WHO Expert Committee. Technical Report Series No 804: <http://apps.who.int/bookorders/anglais/detart1.jsp?codlan=1&codcol=10&codcch=804> (last accessed September 2015)
13. WHO: 1998: Symptom Relief in Terminal Illness: <http://apps.who.int/bookorders/anglais/detart1.jsp?codlan=1&codcol=15&codcch=455> (last accessed September 2015)
14. WHO 2002: defining palliative care: <http://www.who.int/cancer/palliative/definition/en/> (last accessed September 2015)
15. Puchalski C, Ferrell B, Virani R, Otis-Green S, Baird P, Bull J, M.A., Chochinov H, George Handzo G, Nelson-Becker H, Prince-Paul M, Pugliese K, Sulmasy D. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *J Palliat Med* 2009;12:885-904.
16. Doyle D, Hanks G, Cherny N, Calman K. *Oxford Textbook of Palliative Medicine*. Third edition. Oxford University Press, Oxford, 2005.
17. De Graaff A, Teunissen S, Zylicz Z. *Palliatieve zorg: Richtlijnen voor de praktijk*. Laren, 2006. ISBN 90-72175—37-9.
18. De Graaff A, van Bommel J, van Deijck R, van den Eynden B, Krol R, Oldenmenger W, Vollaard E. *Palliatieve zorg: Richtlijnen voor de praktijk*. Laren, 2010. ISBN 978-90-72175—37-9.
19. Puchalski CM, Kilpatrick SD, McCullough ME, Larson DB. A systematic review of spiritual and religious variables in Palliative Medicine, American Journal of Hospice

- and Palliative Care, Hospice Journal, Journal of Palliative Care, and Journal of Pain and Symptom Management. *Palliat Support Care* 2003 Mar;1(1):7-13.
20. Sinclair S, Pereira J, Raffin S. A thematic review of the spirituality literature within palliative care. *J Palliat Med* 2006 Apr;9(2):464-79
 21. Scobie G, Caddell C. Quality of life at end of life: Spirituality and coping mechanisms in terminally ill patients. *The Internet Journal of Pain, Symptom Control, and Palliative Care* 2005;4(1)
 22. Hills J, Paice JA, Cameron JR, Shott S. Spirituality and distress in palliative care consultation. *J Palliat Med* 2005;8(4):782-8.
 23. Vernooij-Dassen MJ, Groot MM, van den Berg J, Kuin A, van der Linden BA, van Zuylen L, Crul BJ, Grol RP. Consultation in palliative care: the relevance of clarification of problems. *Eur J Cancer* 2007;43:316-322.
 24. EAPC taskforce spiritual care: <http://www.eapcnet.eu/Themes/Clinicalcare/Spiritual-careinpalliativecare.aspx> (last accessed September 2015)
 25. Unruh AM, Versnel J, Kerr N. Spirituality unplugged: a review of commonalities and contentions, and a resolution. *Can J Occupational Ther* 2002; 69: 5-19.
 26. Buck HG. Spirituality: concept analysis and model development. *Holist Nurs Pract* 2006 Nov-Dec;20(6):288-92.
 27. Burkhardt M. "Spirituality: An Analysis of The Concept," *Holist Nurs Pract* 1989;May:60-77
 28. Astrow A., Pulchalski C, Sulmasy D. Religion, Spirituality, and Health Care: Social, Ethical, and Practical Considerations. *Am J Med* 2001;110:283-287.
 29. Speck P, Higginson I, Addington-Hall J. Spiritual needs in health care. *BMJ* 2004 Jul 17;329(7458):123-4
 30. Dutch Guideline Spiritual Care in Palliative Care: <http://www.oncoline.nl/spiritual-care>. (last accessed September 2015)
 31. Schols JM, Crebolder HF, van Weel C. Nursing home and nursing home physician: the Dutch experience. *J Am Med Dir Assoc* 2004 May-Jun;5(3):207-12.
 32. Conroy S, Van Der Cammen T, Schols J et al. Medical services for older people in nursing homes--comparing services in England and the Netherlands. *J Nutr Health Aging* 2009;13:559-563.
 33. Elderly Care Physician: vocational training: <http://www.verenso.nl/ouderengeneeskunde/de-opleiding/> (last accessed September 2015)
 34. Daaleman TP, Williams CS, Hamilton VL, Zimmerman S. Spiritual care at the end of life in long-term care. *Med Care* 2008 Jan;46(1):85-91.
 35. Zuurmond WA in: *Zinervaring in de zorg, over de betekenis van spiritualiteit in de gezondheidszorg*. red. Jochemsen H en van Leeuwen R. Assen: van Gorcum 2005.
 36. Culliford L.: Spirituality and clinical care, *BMJ* 2002, Dec 21;325(7378):1434-5.
 37. Curlin FA, Chin MH, Sellergren SA, Roach CJ, Lantos JD. The association of physicians' religious characteristics with their attitudes and self-reported behaviours regarding religion and spirituality in the clinical encounter. *Med Care* 2006;44:446-453.
 38. Monroe MH, Bynum D, Susi B, Phifer N, Schultz L, Franco M, MacLean CD, Cykert S, Garrett J. Primary care physician preferences regarding spiritual behaviour in medical practice. *Arch Intern Med* 2003;163:2751-2756.
 39. Sulmasy DP. Spiritual issues in the care of dying patients: ". . . it's okay between me and god". *JAMA* 2006;296:1385-1392.
 40. Becker J, de Hart J. *Godsdienstige veranderingen in Nederland. Sociaal en Cultureel Planbureau*. Den Haag, 2006.
 41. Centraal Bureau voor de Statistiek, CBS. *Sterfte aan dementie*. Statistisch kwartaalblad over de demografie van Nederland 2003;51(2):24-8.
 42. 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;53:299-305.
 43. Seitz D, Purandare N, Conn D. Prevalence of psychiatric disorders among older adults in long-term care homes: a systematic review. *Int Psychogeriatr* 2010;22(7):1025-39
 44. van der Steen JT, Radbruch L, Hertogh CPM, de Boer ME, Hughes JC, Larkin P, Francke AL, Jünger S, Gove D, Firth P, Koopmans RTCM, Volicer L; on behalf of the European Association for Palliative Care (EAPC). White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* 2014 Mar;28(3):197-209
 45. Bonelli RM, Koenig HG. Mental disorders, religion and spirituality 1990 to 2010: a systematic evidence-based review. *J Relig Health* 2013 Jun;52(2):657-73.
 46. Hall S, Petkova H, Tsouros A, Costantini M, Higinson I. Palliative care for older people: better practices. World Health organization, Regional Office in Europe, 2011. <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/cancer/publications/2011/palliative-care-for-older-people-better-practices> (last accessed September 2015)
 47. van der Steen JT. Dying with dementia: what we know after more than a decade of research. *J Alzheimers Dis* 2010;22(1):37-55.
 48. van der Steen JT, Arcand M, Toscani F, de Graas T, Finetti S, Beaulieu M, Brazil K, Nakanishi M, Nakashima T, Knol DL, Hertogh CM. A family booklet about comfort care in advanced dementia: three-country evaluation. *J Am Med Dir Assoc* 2012 May;13(4):368-75
 49. Hughes J, Lloyd Williams M, Sachs G. *Supportive Care for the person with Dementia*. 2010, Oxford University Press. ISBN 978-0-19-955413-3.
 50. Greenhalgh T. How to read a paper: Papers that summarize other papers (systematic reviews and meta-analyses). *BMJ* 1997;315:672
 51. Mays N, Pope C. Qualitative research in health care. Assessing quality in qualitative research. *BMJ* 2000 Jan 1;320(7226):50-2.
 52. Pope C, Van Royen P, Baker, R. (2002). Qualitative methods in research on healthcare quality. *Quality and Safety in Health Care* 2002;11:148-152.
 53. Reeves S, Kuper A, Hodges BD. Qualitative research methodologies: ethnography. *BMJ* 2008;337:a1020

Chapter 2

The concept of spirituality at the end of life

Spirituality at the End of Life:
Conceptualization of Measurable Aspects-
A systematic Review

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ABSTRACT

Background

Although spiritual caregiving is a key domain of palliative care, it lacks a clear definition, which impedes both caregiving and research in this domain.

Objectives

The aim of this study was to conceptualize spirituality at the end-of-life by identifying dimensions, based on instruments measuring spirituality in end-of-life populations.

Methods

A systematic literature review was conducted. Literature published between 1980 and 2009, focussing on instruments measuring spirituality at the end of life was collected from the Pubmed, Cinahl and PsycInfo databases. Inclusion criteria were: (1) the studies provide empirical data collected with an instrument measuring spirituality or aspects of spirituality at the end of life; (2) the data report on a (sub-group) of an end-of-life population, and (3) the instrument is available in the public domain. Content validity was assessed according to a consensus-based method. From the items of the instruments, three investigators independently derived dimensions of spirituality at the end of life.

Results

In 36 articles that met the inclusion criteria we identified 24 instruments. Nine instruments with adequate content validity were used to identify dimensions of spirituality. To adequately represent the items of the instruments and to describe the relationships between the dimensions, a model defining spirituality was constructed. The model distinguishes the dimensions of Spiritual Well-being (e.g. peace), Spiritual Cognitive Behavioral Context (Spiritual Beliefs, Spiritual Activities and Spiritual Relationships), and Spiritual Coping, and also indicates relationships between the dimensions.

Conclusions

This model may help researchers to plan studies and to choose appropriate outcomes, and assist caregivers in planning spiritual care.

INTRODUCTION

This article conceptualizes spirituality at the end of life, which is, in addition to physical and psychosocial aspects, one of the three domains of palliative care.¹ Spiritual issues frequently become more relevant at the end of life. Moreover, patients often experience spiritual distress at the end of life, and the importance of its alleviation, as a contribution to spiritual and psycho-social well-being, has been acknowledged in various studies.^{2,3} In a study of cancer patients it was found that the existential domain was more important in determining quality of life of patients with local and metastatic diseases than that of patients with no evidence of disease.⁴ In a study of 340 patients with advanced disease, most of the patients considered spiritual issues as important. Over 80% indicated that being prepared to die, being at peace with God, praying, and feeling that one's life is complete is important at the end of life.⁵ In a study on spiritual well-being and distress performed in a palliative care service of an academic medical center, over 90% of the patients reported that spirituality was important to them. A significant relationship was found between religious coping and physical and emotional well-being subscales of the Functional Assessment of Cancer Therapy (FACT-G), as well as the FACT-G total score.⁶ In sum, spirituality contributes to good quality of life, which is the main goal of palliative care.⁷

Even though there is broad consensus on the importance of spiritual care at the end of life, in clinical practice, attention paid to spiritual care is limited.⁸ One barrier for the provision of spiritual care provision is lack of consensus on conceptualization.^{9,10} Definitions of spirituality that have been reported in the literature so far are only to a certain extent compatible. "Meaning" is included in many definitions, but there is a lack of consensus on other elements. Daaleman et al¹¹ approached the concept from the angle of spiritual beliefs and activities: 'Those beliefs, practices and stories that respond to a shared human need for meaning', whereas Steinhäuser et al¹² defined spirituality as 'The search for attention to the ultimate meaning and purpose in life, often involving a relationship with the transcendent', and focused on the construct of 'being at peace'. In a recent definition, Puchalski et al¹³ emphasized the importance of connectedness as an element of spirituality, whereas King and Koenig¹⁴ emphasized the possible relationship between (aspects of) spiritual well-being and spiritual beliefs and activities. Aspects of spiritual activities (e.g. religious rituals) and the possible outcomes of such activities (e.g. experience of connectedness) are used interchangeably in the various definitions. Due to the lack of consensus on a clear definition, researchers and practitioners are given little guidance in assessment of spiritual needs at the end of life, which is a barrier to the provision of adequate spiritual care at the end of life.

The aim of this study is to conceptualize spirituality by identifying dimensions of spirituality at the end of life, based on instruments measuring (aspects of) spirituality in end-

of-life populations. We adopted this empirical approach because it may reconcile domains into a concept that is more useful in practice and research than what has been achieved by other, more theoretical approaches. Our systematic review of instruments measuring spirituality conceptualizes spirituality, based on an analysis of the items of instruments that have been used to measure spirituality in end-of-life populations.

The following two research questions were addressed:

- 1) Which instruments measuring aspects of spirituality in end-of-life populations are available, and what is the content validity of these instruments?
- 2) Which dimensions that may conceptualize spirituality can be derived from the items of these instruments?

METHODS

The following databases were systematically searched: Medline, PsycInfo, and CINAHL, and the timeframe was January 1st, 1980 to August 27th, 2009. The search combined three search fields: 1) palliative care / end-of-life, 2) spirituality, and 3) a methodological search filter to identify instrument measurement properties. These fields were searched with controlled vocabulary (MESH in case of PubMed) and free-text terms and synonyms were searched for in titles and abstracts. We refer to the Appendix for the full search strategy.

The following inclusion criteria were applied:

- Studies provide empirical data on an instrument measuring spirituality or aspects of spirituality at the end of life;
- Data exclusively report on populations or identifiable sub-groups of patients with life-threatening disease. The following criteria for a life-threatening disease were applied:
 - Advanced disease and/or otherwise a situation in which the patient will die within a short period, such as terminally ill cancer patients or patients with a life-expectancy of 6 weeks or less
 - Cancer stage IV and/or
 - Receiving palliative care (such as hospice patients, patients in a palliative care unit, or identified by a palliative consultation service)
- The instrument is available in the public domain.

The following strategy was followed: In the first phase, the primary reviewer (MJG) selected potentially relevant articles based on title and abstract. To refine the selection criteria, a pilot set of abstracts was independently reviewed by two other researchers (MAE and JTS), and this resulted in standardization of the selection criteria. These criteria, when needed, were applied to the initially selected publications in an iterative process. In the second phase, the primary reviewer (MJG) retrieved and read the full texts of the selected publications. This procedure was also applied to a pilot set of articles that was independently reviewed by one other researcher (MAE). This process also resulted in standardization of the selection criteria, which, if needed, were applied to the selected publications (MJG). It was decided to select not only instruments on spirituality, but also quality-of-life instruments with a sub-scale measuring spirituality. Ambiguous cases were discussed with two other researchers (MAE and JTS), until consensus was achieved. Finally, the instruments were retrieved.

After searching the literature and selecting the instruments, content validity was deter-

mined by applying the Terwee et al. criteria as part of an assessment of psychometric properties.¹⁵ To obtain a positive score for content validity, the development of the instrument had to meet the following criteria:

1. The instrument is available in the public domain (because it was one of the inclusion criteria this criterion was always met);
2. The intended measurement aim of the questionnaire, the target population, and the process of item-selection for the instrument are clearly described;
3. The target population is involved in the item-selection in combination with reference to the literature or consultation with experts.

Based on these criteria, the instruments could be scored '+', '+/-', '- ' or 'o', as follows:

- Positive (+) all three criteria are met
- Intermediate (+/-) criterion three was not met
- Negative (-) criteria two and three were not met
- Not determined (o) no information on content validity

We also studied whether content validity referred specifically to end-of-life populations, because some instruments were originally developed for other populations. All the items of the instruments were studied independently by three researchers (MJG, JTS, MAE) to identify overarching aspects of spirituality at the end of life. Each of the researchers independently (1) defined the smallest possible set of categories based on the content of the instrument items, and (2) verified that all the items fitted into the categories. Subsequently, findings were discussed by three researchers (MJG, JTS, MAE) until consensus was achieved on the labelling process.

RESULTS

The search resulted in 2900 hits: 1165 in Pubmed, 1296 in CINAHL and 439 in PsycInfo. Figure 1 shows the process of including abstracts and full text articles. The 39 articles that met the inclusion criteria described 24 instruments measuring spirituality.

Figure 1 presents a flow chart illustrating the article and instrument selection process.

Content validity could not be determined in five out of 24 instruments (21%). These included three instruments that mainly focused on religion: the FICA⁶ and two instruments developed at the Fetzer Institute: the subscales for Forgiveness and Religious Meaning³⁷. Further, we were unable to find the Spiritual Perspective Scale³⁷, because reference was made to an unpublished manuscript. Finally, the Spiritual Well-being Questionnaire⁴⁸ was an adaption from the Spiritual Well-being Scale⁵¹, with the word God substituted by the word Spirituality and the word 'today' added to each item. No information on content validity was found.

Of the remaining 19 instruments (79%), 14 had a positive content validity score, three had an intermediate score, and two had a negative score. The content validity of nine instruments (38% of the total of 24 instruments) was determined in end-of-life populations. Three instruments measured spirituality: the Spiritual Needs Inventory (SNI)²⁴, the Jarel Spiritual Well-being Scale⁵³ and 'Are you at peace?'⁷¹², whereas six instruments measured quality of life, with a subset of items on spirituality: the Quality of Life at the End of Life Measure (QUAL-E)⁴⁵, the Hospice Quality of Life Index³¹, the Missoula Vitas Quality of

Life Index⁶², the McGill Quality of Life Questionnaire²², the Good Death Inventory³³ and the Needs Assessment for Advanced Cancer Patients (NA-ACP³⁹).

Table 1 presents the 24 instruments measuring spirituality and their content validity.^{6,7,8,12,16-64}

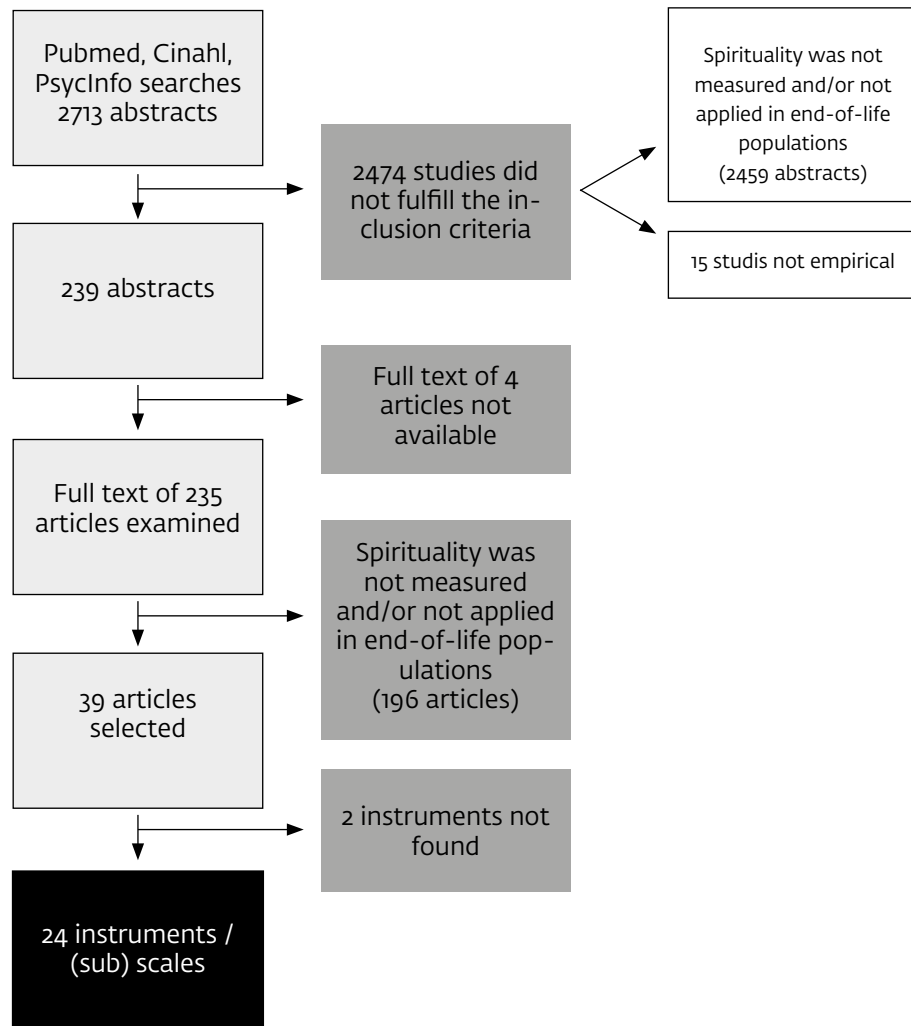


Figure 1. Flow chart illustrating the article and instrument selection process.

Table 1. Identified Instruments and content validity
a) The 9 instruments in which content validity met the criteria and in which an end-of-life population was involved

Instrument	Included articles in which instrument is used	End-of life population in included articles (n)	Content validity of the instrument	
			Score	Reference
Spiritual Needs Inventory (SNI)	Hermann CP, 2007 ²⁵	Hospice patients (n=100)	+	Hermann CP, 2006 ²⁴
	Hermann CP, 2006 ²⁴	Hospice patients (n=100)		
JAREL Spiritual Well-being Scale	Prince-Paul M, 2008 ³⁸	Adult hospice patients (n=50)	+	Hungelman J et al., 1996 ⁵³
'Are you at peace?'	Steinhauser K et al., 2006 ¹²	Stage IV cancer, COPD FEV1<1l, CHF ejection fraction <20 % (n=248)	+	Steinhauser K et al., 2006 ¹²
Quality of Life at the End of Life Measure (QUAL-E)	Steinhauser K et al., 2004 ⁴⁵	Stage IV cancer, COPD FEV1<1l, CHF ejection fraction <20 % (n=248)	+	Steinhauser K et al., 2004 ⁴⁵
Hospice Quality of Life Index	McMillan SC & Weitzner M., 1998 ³²	Home-based hospice care (n=118)	+	McMillan SC, 1996 ³¹
	McMillan SC, 1996 ³¹			
Missoula Vitas QOL (MVQOL)	McMillan SC & Mahon M, 1994 ³⁰	Hospice patients (n=68)	+	Byock IR & Merriman MP, 1998 ⁶²
	Williams AL et al., 2005 ⁴⁷	AIDS, CD4<200/mm3, viral load >100.000/ml, co morbidity (n=58)		
Missoula Vitas QOL (MVQOL)	Steele LL et al., 2005 ⁴⁴	Convenience sample of terminally ill patients (n=129)	+	Byock IR & Merriman MP, 1998 ⁶²
	Schwartz CE et al., 2005 ⁴¹	Hospice patients (n=31)		
	Steinhauser K et al., 2004 ⁴⁵	Stage IV cancer, COPD FEV1<1l, CHF ejection fraction <20 % (n=248)		

b) The 15 other instruments in which an end-of-life population was not involved

Instrument	Included articles in which instrument is used	End-of life population in included articles (n)	Content validity of the instrument		Instrument	Included articles in which instrument is used	End-of life population in included articles (n)	Content validity of the instrument	
			Score	Reference				Score	Reference
McGill Quality of Life Questionnaire	Sherman DW et al., 2005 ⁴²	Tumor that metastasized despite chemo, radiation, or hormonal therapy, AIDS, >100.000 viral load, CD4 0-200 cells/mm ³ , one or more hospital admissions in the last year (n=101)	+	Cohen SR & Mount BM, 2000 ²²	Palliative Outcome Scale (POS)	Bausewein C et al., 2005 ¹⁸	Hospital support team, palliative care units, hospice (n=118)	+	Hearn J, Higginson IJ., 1997 ⁶³
	Bentur N & Resnizky S, 2005 ¹⁹	Advanced cancer, admitted in home hospice units (n=100)				Brandt HE et al., 2005 ²⁰	Life expectancy of 6 weeks or less, nursing homes (n=448)		
	Scobie G & Caddell C, 2005 ⁷	Terminally ill patients in hospices (n=120)				Higginson IJ & Donaldson N, 2004 ²⁶	Patients receiving home or hospice palliative care (n=140)		
	Tang WR et al., 2004 ⁴⁶	Participants of two hospice programs (n=60)				Hearn J & Higginson IJ, 1999 ²³	Patients receiving Palliative Care (n=148)		
Good Death Inventory	Cohen SR & Mount BM, 2000 ²²	Subset Palliative Home Care (n=47)	+	Miyasita M et al., 2008 ³³	The Patient Dignity Inventory	Chochinov H et al., 2008 ²¹	Patients receiving Palliative Care (n=253)	+	Chochinov H et al., 2007 ⁶⁴
	Miyasita M et al., 2008 ³³	Bereaved family members of cancer patients who had died (n=189)			The Functional Assessment of Chronic Illness	Ando M et al. 2008 ¹⁷	Cancer Patients from the Palliative Care Unit (n=30)	+	Peterman AH et al., 2002 ⁵²
Needs Assessment for Advanced Cancer Patients (NA-ACP)	Rainbird KJ et al., 2009 ⁵⁰	Incurable cancer with life expectancy between 3 months and 2 years (n=246)	+	Rainbird KJ et al., 2005 ³⁹	Therapy-Spiritual Well-being Scale (FACIT-SP)	Hills J et al., 2005 ⁶	Patients of Palliative Care Consult Service (n=31)		
	Rainbird KJ et al. 2005 ³⁹	Incurable cancer with life expectancy between 3 months and 2 years (n=246)				Steinhauser K et al., 2004 ⁴⁵	Stage IV cancer, COPD FEV1<1l, CHF ejection fraction <20% (n=248)		
						Nelson CJ et al., 2002 ³⁵	Terminally ill patients diagnosed with cancer and AIDS (n=162)		

Instrument	Included articles in which instrument is used	End-of life population in included articles (n)	Content validity of the instrument	
			Score	Reference
Royal Free Interview	McCoubrie RC & Davies AN, 2006 ²⁹	Metastatic or incurable cancer, hospice (n=85)	+	King M et al., 2001 ⁵⁵
Spiritual Involvement and Beliefs Scale (SIBS)	Mystakidou K et al., 2007 ³⁴	Patients in a palliative care unit (n=82)	+	Hatch RL et al., 1998 ⁵⁶
Spiritual Transcendence Measure (STM)	Leung KK et al., 2006 ²⁸	Terminal cancer patients, palliative care units (n=37)	+/-	Leung KK et al., 2006 ²⁸
Skalen zur Erfassung von Lebensqualität bei Tumorkranken, modified version (SELT-M)	Ando M et al., 2007 ¹⁶	Terminally ill cancer patients (n=12)	+/-	Wegberg van B et al., 1998 ⁵⁴
Fetzer Institute, Subscale Daily Spiritual Experience	Park C, 2008 ³⁷	Advanced CHF, estimated mortality rate 30-40% annually (n=111)	+/-	Underwood LG, Teresi JA., 2002 ⁵⁸
Spiritual Wellbeing Scale (SWBS)	Ruszicka S et al., 2007 ⁴⁰	Terminal Cancer, 'Malignant with anticipated death' (n=50)	-	Paloutzian RF & Ellison CW, 1982 ⁵¹
	McCoubrie RC & Davies AN, 2006 ²⁹	Metastatic or incurable cancer, hospice (n=85)		
	Sherman DW et al., 2005 ⁴²	Advanced Cancer, life expectancy less than a year, HIVRNA>100.000, CD40-200 (n=101)		
	Tang WR et al., 2004 ⁴⁶	Participants of two hospice programs (n=60)		
	Pace JC & Stables JL, 1997 ³⁶	Patients from a community based hospice (n=55)		

Instrument	Included articles in which instrument is used	End-of life population in included articles (n)	Content validity of the instrument	
			Score	Reference
Fetzer Institute, subscale Brief RCOPE	Hills J et al., 200 ⁵⁶	Patients of Palliative Care Consult Service (n=31)	-	Pargament KI et al., 2000 ⁵⁷
Fetzer Institute, subscale Forgiveness, short version	Park C, 2008 ³⁷	Advanced CHF, estimated mortality rate 30-40% annually (n=111)	0	Idler E., 2003 ⁵⁹
Fetzer Institute, subscale Religious Meaning, short version	Park C, 2008 ³⁷	Advanced CHF, estimated mortality rate 30-40% annually (n=111)	0	Pargament KI, 2003 ⁶⁰
Spiritual Assessment Tool FICA	Hills J et al., 200 ⁵⁶	Patients of Palliative Care Consult Service (n=31)	0	Puchalski C, Romer AL, 2000 ⁶¹
Spiritual Perspective Scale	Ita DJ, 1995 ²⁷	Home hospice patients (n=69)	0	Ita DJ, 1995 ²⁷
Spiritual Well-Being Questionnaire	Wlodarczyk N, 2007 ⁴⁸	Patients in in-patient hospice unit (n=10)	0	Wlodarczyk N., 2007 ⁴⁸

Note: the content validity criteria (see method section):

- + All the Validity Criteria are met
- +/- All the Validity Criteria are met, except target population was not involved in item selection
- Item selection was not described clearly and target population was not involved in item selection
- o No relevant information on content validity

In the process of identifying overarching aspects of spirituality at the end of life, the three researchers independently labelled all items on the 24 instruments, comparing and discussing their results until consensus was achieved on the labelling. For instance: 'I feel peaceful' was labelled 'Peace' (FACIT-SP⁵²); 'Belief in afterlife' was labelled 'Beliefs' (Spiritual Transcendence Measure²⁸). There were many items in which different kinds of positive feelings were described, e.g. 'thankful', 'feel good', 'enjoyable', 'having some pleasure'. These were categorized as: 'Positive Affect'. Positive affect represented the dimension Spiritual Well-being, along with peace, harmony, trust, hope, acceptance, purpose, meaning, connectedness, completion, fulfilment, and comfort.

Within categories, there was variability in items. The items labelled 'Beliefs' may refer to an inventory, for instance, 'Do you have a specific religion?' (Royal Free Interview⁵³), while other items were related to the content or meaning of the beliefs to the patient: 'I think about how my life is a part of a larger spiritual force' (Brief RCOPE⁵⁷), or refer to the needs or problems concerning the Spiritual beliefs, such as 'I desire to be closer to God or in union with the divine' (Daily Spiritual Experience Scale⁵⁸). We categorized these as Spiritual Beliefs. The items labelled prayer, meditation, reading religious texts and attending religious services were categorized as Spiritual Activities. Many items refer to 'Spiritual Relationships': relationships with people from the religious community, e.g. 'talk with someone about religious or spiritual issues' (Spiritual Needs Inventory²⁴), relationships with loved ones, e.g. 'There is someone in my life with whom I can share my deepest thoughts' (QUAL-E⁴⁵), relationship with pastor, vicar or priest, e.g. 'Being able to see your priest, chaplain or minister' (NA-ACP³⁹), and relationship with God, e.g. 'Bargained with God to make things better' (Brief RCOPE⁵⁷). We categorized these as Spiritual Relationships. We combined Spiritual Beliefs, Spiritual Activities and Spiritual Relationships into the dimension of Spiritual Cognitive Behavioural Context.

We only labelled three items as Spiritual Coping, e.g. 'Dealing with spiritual issues of death and dying' (NA-ACP³⁹). We considered the dimension Spiritual Coping as all behaviour and cognitions aimed at decreasing of perceived distress and increasing spiritual well-being by means of Spiritual Beliefs, Spiritual Activities, and Spiritual Relationships. Ten instruments had a total of 38 items on the association between Spiritual Coping and other dimensions, 22 of these were in the Brief RCOPE.

A preliminary model was constructed and tested for comprehensiveness by fitting all items from the nine instruments (Table 1) into the dimensions of the model, again based on the independent opinions of the reviewers, followed by a consensus procedure. A minimally revised model allowed all items to fit, and this model is presented in Figure 2. All identified aspects of the nine instruments that met the criteria for content validity were completely covered by the three dimensions of Spiritual Well-being, Spiritual Cognitive Behavioural Context, and Spiritual Coping and associations between these dimensions. Moreover, we could construct the same model with the items of the 15 instruments that did not meet the criteria for content validity for reason of not being specifically developed for end-of-life populations.

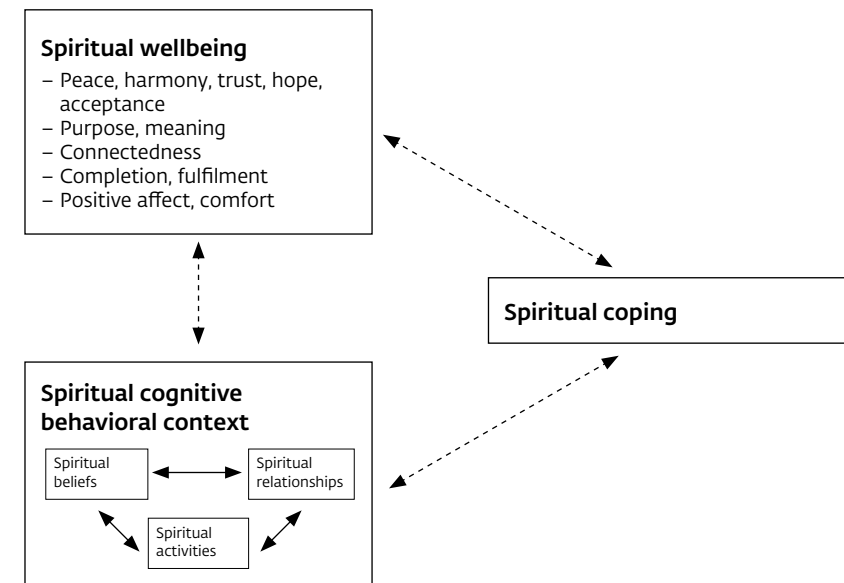


Figure 2. A model for the conceptualization of spirituality at the end of life

Table 2 shows the number of items representing the dimensions, and their associations. Out of a total of 291 items, 94 items (32%) were related to the dimension Well-being, 46 (16%) to Beliefs, 23 (8%) to Activities, and 63 (22%) were related to Relationships. Three items (1%) were related to Spiritual Coping, and a total of 62 items (21%) represented associations between the dimensions. The dimensions of spirituality are represented differently in the instruments.

Most instruments include various dimensions. The Spiritual Well-being Scale, for instance, has ten items concerning Spiritual Well-being and six concerning Spiritual Relationships, three on the association between these dimensions and one on the association between Spiritual Well-being and Spiritual Activities (Table 2). Eight of the items of the FACIT-SP⁵² are related to Spiritual Well-being, two to the association between Spiritual Well-being and Spiritual Beliefs, and one is related to the association between Spiritual Well-being and Spiritual Coping. The Missoula-Vitas Quality of Life Index⁶² includes four items on Spiritual Well-being and two on Spiritual Beliefs. Four more items on Spiritual Well-being concerned changes caused by the illness, e.g. 'Thanks to my illness, I was able to make valuable experiences I would not have gained otherwise' (SELT-M¹⁶).

Table 2. Number of instrument items representing content of spirituality**Number of items on spirituality**

Instrument	Total	Wellbeing	Spiritual Cognitive Behavioral		Context		Items indicating relationships between dimensions	
			Beliefs	Activities	Relationships	Coping	Content	Number
Spiritual Needs Inventory (SNI)	16	2	-	6	8	-		
JAREL Spiritual Well-being Scale	20	7	6	1	4	-	Relationships-Spiritual Coping Spiritual Wellbeing-Spiritual Coping	1 1
'Are you at peace?'	1	1	-	-	-	-		
Quality of Life at the End of Life Measure (QUAL-E)	8	3	-	-	2	-	Spiritual Wellbeing- Relationships	3
Hospice Quality of Life Index	6	3	-	-	3	-		
Missoula Vitas Quality of Life Index	6	4	2	-	-	-		
McGill Quality of Life Questionnaire	7	5	1	-	1	-		
Good Death Inventory	15	7	1	-	3	-	Spiritual Wellbeing-Relationships	3
Needs Assessment for Advanced Cancer Patients (NA-ACP)	11	4	1	-	4	1	Beliefs-Spiritual Coping Spiritual Wellbeing-Spiritual Coping	1 1
Spiritual Wellbeing Scale (SWBS)	20	10	-	-	6	-	Spiritual Wellbeing-Relationships	3
Spiritual Transcendence Measure (STM)	19	10	1	1	3	-	Spiritual Wellbeing-Activities Spiritual Wellbeing-Activities Spiritual Wellbeing-Spiritual Coping Relationships-Spiritual Coping	1 2 1 1
The Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale (FACIT-Sp)	11	8	-	-	-	-	Spiritual Wellbeing-Beliefs	2
Skalen zur Erfassung von Lebensqualität bei Tumorkranken, modified version (SELT-M)	8	5	-	-	-	1	Spiritual Wellbeing-Spiritual Coping Spiritual Wellbeing-Spiritual Coping	1 2
Royal Free Interview	13	-	9	2	1	-	Beliefs-Spiritual Coping	1
Spiritual Involvement and Beliefs Scale (SIBS)	26	3	6	8	5	1	Spiritual Wellbeing-Activities Spiritual Wellbeing-Beliefs	2 1
Fetzer Institute, subscale Brief RCOPE	48	-	10	2	14	-	Beliefs-Spiritual Coping Activities-Spiritual Coping Relationships-Spiritual Coping	1 6 15
Fetzer Institute, Subscale Daily Spiritual Experience Scale	9	4	-	-	1	-	Spiritual Wellbeing-Beliefs Spiritual Wellbeing-Activities Activities-Spiritual Coping	2 1 1
Fetzer Institute, subscale Forgiveness, short version	3	1	1	-	1	-		
Fetzer Institute, subscale Religious Meaning, short version	2	2	-	-	-	-	Spiritual Wellbeing-Beliefs	1
Spiritual Perspective Scale	10	-	3	3	3	-	Spiritual Wellbeing-Beliefs	1
Spiritual Well-Being Questionnaire	13	10	1	-	1	-	Spiritual Wellbeing-Beliefs	1
Spiritual Assessment Tool FICA	13	-	4	-	3	-	Beliefs-Spiritual Coping Relationships-Spiritual Coping	2 3
Palliative Outcome Scale (POS)	3	2	-	-	1	-		
The Patient Dignity Inventory	3	3	-	-	-	-		

DISCUSSION

This study aimed to conceptualize spirituality by identifying dimensions based on instruments measuring spirituality or aspects of spirituality in end-of-life populations. From 2900 hits in three databases, 39 articles and 24 instruments were identified in the literature. Fourteen instruments met the requirements for content validity, and in nine of these instruments the content validity was assessed in an end-of-life population. The variety of instruments in the understudied domain of spirituality at the end of life was greater than we had anticipated.

From the items of these nine instruments a conceptual model of spirituality was constructed, with the following dimensions: Spiritual Well-being, Spiritual Cognitive Behavioural Context (including Spiritual Beliefs, Spiritual Activities and Spiritual Relationships), Spiritual Coping, and associations between these dimensions. We did not find any instruments that focussed on satisfaction with spiritual care.

How does the model we developed relate to previous definitions of spirituality? Vachon et al.⁶⁵ defined spirituality as ‘a developmental and conscious process, characterized by two movements of transcendence: either deep within the self or beyond the self’. This definition was based on a conceptual analysis of definitional elements of spirituality identified by reviewing the empirical literature. Eleven different themes were listed, for example ‘meaning’ and ‘faith and beliefs’, but these domains had different levels of abstraction, for example ‘conscious nature’ was believed to transcend all other themes. Nevertheless, the authors did not fit the elements into a conceptual or hierarchical model.⁶⁶ Puchalski et al.¹¹ recently published a consensus report in which they included an agreed-upon definition: ‘the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred’. This definition comprises the three dimensions of our model: Spiritual Well-being (meaning and purpose, connectedness) and Spiritual Cognitive Behavioural Context (relationships with others, beliefs) and Spiritual Coping (seek and express). Our model therefore concurs with this definition. We believe that our model has additional value, in that it not only distinguishes dimensions, but also recognizes the different nature of those dimensions and their relationships, including extensive operationalization of the dimensions.

We consider the dimension Spiritual Well-being in our model as a care outcome, to which Spiritual Coping, Spiritual Activities, Spiritual Beliefs and Spiritual Relationships can contribute. As the dimension of Spiritual Coping was found in only three of 24 included instruments, the importance of this dimension must therefore be verified in further research. The content validity of some instruments that are frequently used in end-of-life research (e.g. the Spiritual Well Being Scale, the FACIT-SP, and the Palliative care Outcome Scale) was not determined in end-of-life populations.

Benefits of our model are the following: it contains only aspects that were demonstrated to be empirically viable, and were distinguished in dimensions, thus simultaneously separating content and level of abstraction. Users may wish to focus on one or two dimensions which are relevant, for instance for assessment or research. The model aims to be comprehensive, and thus covers the full scope of the concept of spirituality, which may be useful for the development or assessment of instruments. It may help in the formulation of research hypotheses (e.g. the relationships between the dimensions). The model may thus contribute to better understanding of spirituality at the end of life. Because the mo-

del could equally well be constructed from instruments developed especially for palliative care, or from more generic instruments, the model may be valid both in and beyond end-of-life situations, thus allowing study of how the dimensions in the model, including their associations, vary in importance during the changing health status of the patient. Future research should test this assumption, and also the usefulness of the model in practice.

A limitation of our study is that in the process of reviewing the literature, the primary reviewer made the first selection of articles, based initially on title and abstract, and later on the full texts of the articles, although the other two researchers were involved in refining and standardizing the selection criteria.

Conclusions

A systematic review of instruments measuring spirituality which are currently being used in end-of-life situations resulted in a comprehensive model conceptualizing spirituality, and distinguishing three dimensions of spirituality and their associations. This model potentially contributes to a better understanding of spirituality at the end of life, and may also be applicable beyond end-of-life situations. It may help researchers to plan studies and choose appropriate outcomes, and assist caregivers in planning spiritual care.

References

1. WHOQOL Group. The World Health Organization Quality of Life Assessment (WHOQOL): position paper from the World Health Organization. *Soc Sci Med* 1995;41:1403-1409.
2. Brown AE, Whitney SN, Duffy JD. The physician's role in the assessment and treatment of spiritual distress at the end of life. *Palliat Support Care* 2006 Mar;4(1):81-6.
3. Block SD. Perspectives on care at the close of life. Psychological considerations, growth, and transcendence at the end of life: the art of the possible. *JAMA* 2001 Jun 13;285(22):2898-905.
4. Cohen SR, Mount BM, Thomas JJN, Mount LF: Existential well-being is an important determinant of quality of life. Evidence from the McGill Quality of life Questionnaire. *Cancer* 1996;77:576-586.
5. Steinhauer KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsy 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.
6. Hills J, Paice JA, Cameron JR, Shott S. Spirituality and distress in palliative care consultation. *J Palliat Med* 2005;8(4):782-8.
7. Scobie G, Caddell C. Quality of life at end of life: Spirituality and coping mechanisms in terminally ill patients. *The Internet Journal of Pain, Symptom Control, and Palliative Care* 2005;4(1).
8. Kuin A, Deliens L, van Zuylen L, Courtens AM, Vernooij-Dassen MJ, van der Linden B, et al. Spiritual issues in palliative care consultations in the Netherlands. *Palliat Med* 2006 Sep;20(6):585-92.
9. Mueller PS, Plevak DJ, Rummans TA. Religious involvement, Spirituality, and Medicine : Implications for Clinical Practice. *Mayo Clin Proc* 2001;76:1225-1235.
10. Breitbart W, Gibson C, Poppito SR, Berg A. Spirituality and meaning in supportive care: Spirituality- and meaning-centered group psychotherapy interventions in advanced cancer. *Support Care Cancer* 2002;10:272-280.
11. Daaleman TP. Religion, Spirituality and the practice of Medicine. *J Am Board Fam Pract* 2004;17: 370-376.
12. Steinhauer KE, Voils CI, Clipp EC, Bosworth HB, Christakis NA, Tulsy JA. "Are You at Peace?" One Item to Probe Spiritual Concerns at the End of Life. *Arch Int Med* 2006;166: 101-105.
13. Puchalski C, Ferrell B, Virani R, Otis-Green S, Baird P, Bull J, Chochinov H, Handzo G, Nelson-Becker H, Prince-Paul M, Pugliese K, Sulmasy D. Improving the Quality of Spiritual Care as a Dimension of Palliative Care: the report of the Consensus Conference. *J Palliat Med* 2009 Oct;12: 885-904.
14. King MB, Koenig HG. Conceptualising spirituality for medical research and health service provision. *BMC Health Serv Res* 2009;9:116.
15. 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.
16. Ando M, Tsuda A, & Morita T. Life review interviews on the spiritual well-being of terminally ill cancer patients. *Support Care Cancer* 2007;15:225-231.
17. Ando M, Morita T, Okamoto T, & Ninosaka Y. One-week Short-Term Life Review interview can improve spiritual well-being of terminally ill cancer patients. *Psychooncology* 2008;17:885-890.
18. Bausewein C, Fegg M, Radbruch L, Nauck F, von, M S, Borasio, G D. et al. Validation and clinical application of the german version of the palliative care outcome scale. *J Pain Symptom Manage* 2005;30:51-62.
19. Bentur N, Resnizky S. Validation of the McGill Quality of Life Questionnaire in home hospice settings in Israel. *Palliat Med* 2005;19:538-544.
20. Brandt HE, Deliens L, van der Steen JT, Ooms ME, Ribbe MW, van der Wal 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.
21. Chochinov H M, Hassard T, McClement S, et al. (2008). The Patient Dignity Inventory: A Novel Way of Measuring Dignity Related Distress in Palliative Care. *J Pain Symptom Manage* 2008;36:559-571.
22. 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;89:1854-1865.
23. Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the Palliative Care Outcome Scale. *Qual Health Care* 1999;8:219-227.
24. Hermann CP. Development and testing of the spiritual needs inventory for patients near the end of life. *Oncol Nurs Forum* 2006;33:737-744.
25. Hermann CP. The degree to which spiritual needs of patients near the end of life are met. *Oncol Nurs Forum* 2007;34:70-78.
26. Higginson IJ, Donaldson N. Relationship between three palliative care outcome scales. *Health Qual Life Outcomes* 2004;2:68.
27. Ita DJ. Testing of a causal model: Acceptance of death in hospice patients. *Omega* 1995;32:81-92.
28. Leung KK, Chiu TY, Chen CY. The influence of awareness of terminal condition on spiritual well-being in terminal cancer patients. *J Pain Symptom Manage* 2006;31:449-456.
29. McCoubrie RC, Davies AN. Is there a correlation between spirituality and anxiety and depression in patients with advanced cancer? *Support Care Cancer* 2006;14:379-385.
30. McMillan SC, Mahon M. The impact of hospice services on the quality of life of primary caregivers. *Oncol Nurs Forum* 1994;21:1189-1195.
31. McMillan SC. The quality of life of patients with cancer receiving hospice care. *Oncol Nurs Forum* 1996;23:1221-1228.
32. McMillan SC, Weitzner M. Quality of life in cancer patients: use of a revised Hospice Index. *Cancer Pract* 1998;6:282-288.
33. 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;35:486-498.
34. Mystakidou K, Tsilika E, Parpa E, Pathiaki M, Patiraki E, Galanos A. et al. Exploring the relationships between depression, hopelessness, cognitive status, pain, and spirituality in patients with advanced cancer. *Arch Psychiatr Nurs* 2007 Jun;21(3):150-161.
35. Nelson CJ, Rosenfeld B, Breitbart W, Galieta M. Spirituality, religion, and depression in the terminally ill. *Psychosomatics* 2002;43:213-220.
36. Pace JC, Stables JL. Correlates of spiritual well-being in terminally ill patients with AIDS and terminally ill persons with cancer. *JANAC* 1997;8:31-42.
37. Park CL. Estimated longevity and changes in spirituality in the context of advanced congestive heart failure. *Palliat Support Care* 2008;6:3-11.

38. Prince-Paul M. Relationships among communicative acts, social well-being, and spiritual well-being on the quality of life at the end of life in patients with cancer enrolled in hospice. *J Palliat Med* 2008;11:20-25.
39. 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;14:297-306.
40. Ruzicka S, Sanchez-Reilly S, Gerety M. Holistic assessment of chronic pain among elders. *Am J Hosp Palliat Care* 2007;24:291-299.
41. 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;8:121-135.
42. Sherman DW, Ye XY, McSherry C, Calabrese M, Parkas V, Gatto M. Spiritual well-being as a dimension of quality of life for patients with advanced cancer and AIDS and their family caregivers: results of a longitudinal study. *Am J Hosp Palliat Care* 2005;22:349-362.
43. Sherman DW, Ye XY, McSherry C, Parkas V, Calabrese M, Gatto M. Quality of life of patients with advanced cancer and acquired immune deficiency syndrome and their family caregivers. *J Palliat Med* 2006;9:948-963.
44. Steele LL, Mills B, Hardin SR, Hussey LC. The quality of life of hospice patients: patient and provider perceptions. *Am J Hosp Palliat Care* 2005;22:95-110.
45. Steinhauer 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;2:3-14.
46. Tang W, Aaronson LS, Forbes SA. Quality of life in hospice patients with terminal illness. *West J Nurs Res* 2004 Feb;26(1):113-28.
47. Williams A, Selwyn PA, Liberti L, Molde S, Njike VY, McCorkle R et al. A randomized controlled trial of meditation and massage effects on quality of life in people with late-stage disease: a pilot study. *J Palliat Med* 2005;8:939-952.
48. Wlodarczyk N. The effect of music therapy on the spirituality of persons in an in-patient hospice unit as measured by self-report. *J Music Ther* 2007;44:113-122.
49. Justo Roll I, Simms V, Harding R. Multidimensional problems among advanced cancer patients in Cuba: awareness of diagnosis is associated with better patient status. *J Pain Symptom Manage* 2009;37:325-330.
50. Rainbird K, Perkins J, Sanson-Fisher R, Rolfe I, Anselme P. The needs of patients with advanced, incurable cancer. *Br J Cancer* 2009 Sep;101(5):759-764.
51. Paloutzian RF, Ellison CW. Loneliness: a Sourcebook of Current Theory. Wiley Interscience New York, NY 1982;224-237.
52. Peterman A.H, 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.
53. Hungelmann J, Kenkel-Rossi E, Klassen L, Stollenwerk R. Focus on spiritual well-being: harmonious interconnectedness of mind-body-spirit -- use of the JAREL Spiritual Well-Being Scale. *Geriatric Nursing* 1996;17(6):262-266.
54. Wegberg van B, Bacchi M, Heusser P, Helwig S, Schaad R, Rohr von E, Bernhard J, Hürny, Castiglione M, Cerny Th. The Cognitive-spiritual dimension: Validation of a questionnaire (SELT-M) in patients with advanced cancer. *Ann Oncol* 1998 Oct;9(10):1091-1096.
55. King M, Speck P, Thomas A. The Royal Free Interview for spiritual and religious beliefs: development and validation of a self-report version, *Psychol Medicine* 2001;31(6):1015-23.
56. Hatch RL, Burg MA, Naberhaus DS, Hellmich LK. The Spiritual Involvement and Beliefs Scale. Development and testing of a new instrument. *J Fam Pract* 1998;46(6):476-486.
57. Pargament KI, Koenig HG, Perez LM. The Many Methods of Religious Coping: Development and Initial Validation of the RCOPE. *J Clin Psychol* 2000;56(4): 519-543.
58. Underwood LG, Teresi JA, The Daily Spiritual Experience Scale. Development, theoretical description, reliability, exploratory factor analysis, and preliminary construct validity using health-related data. *Ann Behav Med* 2002;24(1):22-33.
59. Idler E. Multidimensional Measurement of Religion/ Spirituality for Use in Health Research: Fetzer Institute 2003; www.fetzer.org.
60. Pargament KI. Multidimensional Measurement of Religion/ Spirituality for Use in Health Research: Fetzer Institute 2003; www.fetzer.org.
61. Puchalski C, Romer AL. Taking a Spiritual History Allows Clinicians to Understand Patients More Fully. *J Palliat Med* 2000;3(1):129-137
62. Byock IR, Merriman MP. Measuring quality of life with terminal illness: the Missoula-VITAS quality of life index. *Palliat Med* 1998;12(4):231-244.
63. Hearn J, Higginson IJ. Outcome measures in palliative care for advanced cancer patients: a review. *J Public Health Med* 1997;19(2):193-199.
64. Chochinov HM, Kristjanson LJ, Hack TF, Hassard T, McClement S, Harlos M. Burden to others and the terminally ill. *J Pain Symptom Manage* 2007;36(6):559-571.43.
65. Vachon M, Fillion L, Achille M. A conceptual analysis of spirituality at the end of life. *J Palliat Med* 2009;12:53-59.
66. Steen JT, Gijsberts MJHE, Echteld MAE, Muller T, Ribbe MW, Deliens L. Defining Spirituality at the End of Life. *J Pall Med* 2009;12:677.

Qualitative Research

Chapter 3

The perception of Dutch elderly care physicians of spirituality and their role in spiritual caregiving in nursing homes:

a focus group study

Spiritual End-of-life Care in Nursing Homes:
An Exploratory Study Among Physicians

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SUBMITTED

ABSTRACT

Background

Although spirituality and spiritual care is considered important at the end of life, there are only few empirical studies that report on spiritual caregiving at the end of life, and even less studies have researched the physicians' perspective on the spiritual dimension of palliative care and their role in spiritual caregiving. We aimed to explore how Dutch elderly care physicians view and experience spiritual caregiving at the end of life in nursing homes.

Methods

We performed a focus group study amongst Dutch elderly care physicians practising in nursing homes. To allow for sufficient variability in perceptions and opinions we recruited physicians with variable religious backgrounds, professional interests and experience. The discussions focussed on the following topics: (1) spirituality and spiritual wellbeing at the end of life, (2) the role of the elderly care physician in spiritual caregiving at the end of life, for residents with physical disabilities and residents with dementia, and (3) barriers and facilitators in providing spiritual care at the end of life. Data were analyzed by using thematic analysis.

Results

Participants perceived spirituality primarily as religion, though aspects that are defined as spiritual wellbeing in literature were also mentioned after further reflection, such as being at peace, harmony, trust in an afterlife, the completion of life and meaning. Certain physicians did not feel directly responsible for spiritual caregiving, and lack of expertise and time were mentioned as barriers. Communication with spiritual counsellors was considered to be complex. Difficulty of verbal communication was perceived as a barrier in assessing spiritual needs and spiritual caregiving to residents with dementia.

Conclusions

Training programs may be developed to support physicians in addressing spiritual issues. Spiritual rituals and artefacts, as well as spiritual reminiscence may facilitate nursing home residents with dementia in experiencing in their spirituality. Further research is needed to study if specific training may support elderly care physicians in assessing and addressing spiritual needs and on best practices in providing multidisciplinary spiritual care at the end of life in nursing home residents, including residents with dementia, preferably in cross-national work.

INTRODUCTION

Palliative care can be conceived of as multidimensional care that focuses on symptom relief and the improvement of quality of life of patients and their families, and comprises physical, psychosocial and spiritual aspects.¹ Although in a recent meta-study of qualitative research on end of life care, Edwards et al.² stressed the importance of spirituality and spiritual care, this spiritual dimension seems to be regularly overlooked and underdeveloped in palliative care.³ This study is designed to provide knowledge with which this development may be aided.

There are few empirical studies to date that report on spiritual caregiving at the end of life. Most of these studies focus primarily on the nursing perspective in various care settings. For example, Bailey et al.⁴ described palliative care nurses' understanding of spirituality, and discussed how they recognized and addressed patient's spiritual needs. Hermann⁵ studied spiritual care among 100 hospice patients, emphasizing the importance of spirituality to patients, and of nurses' assessment of spiritual needs near the end of life, in order to provide input for the development of interventions that meets those needs. Daaleman et al.⁶ performed a study on the importance of spiritual care in long-term care settings. They found that spiritual support and spiritual care were associated with better overall care at the end of life for long-term care residents, and that interventions to improve this type of care should be aimed at the interaction between residents and facility staff. Physicians' responsibilities in spiritual caregiving were however not addressed.

Chibnall et al.⁷ specifically addressed physicians' perspectives in a qualitative group study and identified barriers to physicians' psychosocial and spiritual caregiving.

In this article, we present the results of a focus group study amongst Dutch physicians specialized in elderly care medicine. It focuses on spirituality and spiritual end-of-life care in nursing homes, with a particular emphasis on the perspectives of physicians who are responsible for caregiving at the end of life. In the Netherlands, there are approximately 1550 physicians who are specialized in long-term care for frail elderly people, people with dementia and chronic patients with complex health problems: the so-called elderly care physicians.⁸ In most cases, they are employed by Dutch nursing homes and involved in end-of-life care for the 32.000 patients who die in these homes on a yearly basis, i.e. about 25% of all deaths in the Netherlands.⁹ This means that a full-time working Dutch elderly care physician on average provides end-of-life care to more than 20 residents each year. In addition to providing direct medical care, physicians also supervise the resident's multidisciplinary care plan. This implies that the physician has a crucial role in the multidisciplinary care process, more so when the goal of this care process is to provide optimal palliative care, spiritual care included. Consequently the Dutch nursing home setting is eminently suitable for this study.

Recently, more studies were published on spiritual caregiving in dementia and on palliative care in dementia, including spiritual care.^{10,11,12}

The aim of our study is thus to explore how Dutch elderly care physicians perceive spirituality, how they view their role in spiritual caregiving at the end of life and to identify barriers and facilitators in spiritual caregiving at the end of life in nursing homes.

METHODS

Design of the study. A focus group study was chosen because of its suitability to explore this understudied subject in a relatively short period of time. Focus groups allow for probing of conceptualization and attitudes, and explore and clarify topics through interaction between the participants.¹³

Participants. We recruited Dutch elderly care physicians via the professional network of elderly care physicians affiliated to the VU University Medical Center. The Medical Ethics Committee of the VU University Medical Center approved the study, and written informed consent was provided by all participants. To allow for sufficient variability in perceptions and opinions we aimed at six to eight participants per focus group, recruiting physicians with variable religious backgrounds, professional interests and experience. A total of three explorative focus group discussions were conducted, two of which were conducted in the north of the Netherlands and one took place in the South of the Netherlands, which is predominantly Roman Catholic, whereas the rest of the country is predominantly Protestant. All the invited physicians participated. We asked participants to complete a short form with relevant items on demographics and nursing home characteristics (e.g. available disciplines to refer to), as represented in table 1.

Focus group discussions. The three focus group discussions were conducted on April 23rd 2009, September 7th 2009 and January 4th 2010. The discussions were led by an experienced moderator (MTM). The moderator used a topic list with open questions to trigger spontaneous answers and discussion in the focus group participants. The foci of subsequent discussions were developed based on the results of previous discussions. The three focus group sessions focused on the following topics:

1. Spirituality and spiritual wellbeing at the end of life
2. The role of the elderly care physician in spiritual caregiving at the end of life, for residents with physical disabilities and residents with dementia.
3. Barriers and facilitators in providing spiritual care at the end of life

The focus group discussions were audiotaped, and two observers made notes and observed non-verbal behavior (project group members MJG and JTS (two groups), and MJG and MAE (one group)). The audiotaped discussions were transcribed verbatim and checked for accuracy (MJG).

Data analysis. Data were analyzed by using thematic analysis.¹⁴ To contribute to the reliability of the analysis, the transcripts of the focus group discussions were analyzed independently by two researchers (MJG, MTM). First, both researchers coded the transcripts of the discussions, using in vivo coding, and wrote initial memos. The initial coding was discussed, aiming for consensus, and codes were reformulated if applicable. Subsequently, categories were identified by linking codes and data, and overarching themes could be identified. To examine consistency and variance, we paid specific attention to contrasting statements of participants. Interim reports on applicability of the coding, categories and themes were regularly discussed among the authors and subsequently modified when necessary in the research group.

RESULTS

The following themes on spiritual caregiving at the end of life were identified:

1. Views on spiritual caregiving at the end of life, including the subthemes:
 - A. Spirituality and spiritual well-being
 - B. The physicians' own role in spiritual caregiving

And:

2. Barriers and facilitators in spiritual caregiving at the end of life in nursing homes, including the subthemes:
 - A. Lack of time and lack of expertise
 - B. Collaboration with other professionals
 - C. Spiritual caregiving in residents with dementia
 - D. Cultural and generational differences

1. Views on spiritual caregiving at the end of life

The first theme concerns the views of the participants on spiritual caregiving at the end of life, specifically their views on spirituality and spiritual wellbeing and the physician's own role in spiritual caregiving.

A. Spirituality and spiritual well-being

The participants' initial view on spirituality mostly concerned religious aspects, these included religious beliefs, attending mass, and the importance of a spiritual counselor to provide spiritual care. For instance, one physician stated:

"Thinking of spirituality, I automatically think of religion."

This comment was exemplary for how spirituality was initially spontaneously expressed.

After further reflection however, participants also mentioned a wide variety of elements related to spiritual well-being, such as being at peace, harmony, trust in an afterlife, the completion of life and meaning. Some participants associated spiritual well-being with the resident's acceptance of death:

"That someone is ready to die, is at peace with it and has accepted it",

This acceptance might occur once a completion of life was felt:

"And then he told me about his daughter's wedding, and he wanted to attend it. He went to hospital had a blood transfusion, and when he was back I asked him: well, how long are we going to continue doing this? Then at some point he said spontaneously: 'it's ok like this'... Before that he was really busy with "I still want to go on with my life", he still had these little goals, including this wedding ..., and driving around the village in his electric wheelchair. And then you notice a sudden change, like a break."

B. The physician's own role in spiritual caregiving

A number of participants did not consider spiritual caregiving at the end of life their responsibility, and stated this explicitly:

"I have always considered it to belong to the private domain of a patient, not something I should really get involved in."

"...I don't ask about it specifically, no."

Participants also mentioned that in many cases, spiritual care would be organized by the residents themselves, or by relatives.

"I am often surprised that it has already been taken care of [organizing spiritual care for the resident]."

Other participants however felt that they should be receptive to questions from residents on spirituality and (lack of) spiritual wellbeing.

"I don't really ask about it either, but I do respond when people bring it up spontaneously."

Indeed, some other participants were (more) active in exploring spiritual needs in the nursing home residents:

"I think you should assess spiritual care needs as a matter of routine, just like you routinely assess distress, or you routinely go over and revise medication."

Spiritual caregiving nevertheless was seen as distinct from assessing spiritual needs:

"I am able to assess spiritual needs, but no more than that. But I am not going to address spiritual matters, simply because I do not have the expertise [other participants express agreement]."

Ambiguity about the responsibility for spirituality and spiritual well-being of their patients does not withhold the more active physicians to address it in the introductory admission interview with the resident or proxy, as one participant pointed out:

"I consider spirituality to be a private matter, and medical matters are not automatically linked to the spiritual as far as I am concerned. I do not inquire about it, but I will respond when people bring it up. The subject often comes up in an introduction interview, when a resident is admitted to the nursing home. Especially because I almost always ask about advance directives then and about withholding treatment. Then religion will come up, and I think at the end of life I only address these matters when I notice there are issues that stand in the patient's way, when you notice that there are spiritual issues that play a role ..."

2. Barriers and facilitators in spiritual caregiving at the end of life in nursing homes

A. Lack of expertise and lack of time

Lack of expertise and lack of time were mentioned by several participants as barriers to spiritual caregiving; the possibility of receiving spiritual care training was suggested to remedy this lack of expertise.

"I have no idea what I should advise in case of spiritual distress."

"If you want to, you could learn how to do it [spiritual caregiving], ... and there is always the lack of time."

One participant pointed out that as a physician, dealing with spiritual issues is different from dealing with common medical problems:

"... I think you should not make yourself more important than you are as a physician, you don't have an answer for everything [spiritual issues]."

Some physicians were explicit about their own spirituality and reflected on how it affected clinical work and interaction with nursing home residents on their spirituality, as one physician stated:

"...I also have non-rational thoughts on life and death, but very often I think that I cannot impose this upon the other person [the resident]. And I am not saying that I am done reflecting on the subject, just that my philosophy of life, well, is rational ... and I am not really able to discuss this [with a resident] in another way. But when I notice that the conversation is somehow not working, then I would say: 'perhaps it is better for you to talk to someone else.'"

B. Collaboration with other professionals

Participants also discussed their collaboration with other members of the multidisciplinary team on nursing home residents' spiritual issues. The role of the on-staff spiritual counselor in the multidisciplinary team appeared to vary across different nursing homes. For instance, one participant stated that:

"At our nursing home, the spiritual counselor is part of the team, he participates like everyone else. I get detailed reports on [the biography of] residents: the kind of life they lived, illnesses that occurred, worries they had, worries and fears they have now, and the background of these worries and fears."

On the other hand, another participant pointed to the following:

"In my experience spiritual counselors very much do their own thing, and don't"

want to say anything about it [their contact with the resident] to me, but on the other hand they want to hear a lot from me!"

Several participants stated that psychologists however always shared their information with the multidisciplinary team. Psychologists were consequently also thought to be helpful in discussing spiritual needs of nursing home residents, depending on the way they collaborate with the spiritual counselor within the multidisciplinary team. According to one participant:

"In our team we sometimes have the spiritual counselor go to the residents [to discuss spiritual issues], and sometimes the psychologist. They know about each other's work and I am all for it, so to speak, that they learn to refer to each other and this collaboration is still improving."

The different role of the spiritual counsellor and the psychologist also pertains to how one might deal with potentially traumatic life events, as one participant pointed out:

"At our nursing home we really look at the [residents] biography, and if it mentions a divorce, well, that used to be quite traumatic in this region [South of the Netherlands], and it was also held against people for a long time.. And at the end of their lives people go back to these events..... To me, it was very important to know if and how the divorce is related to religious concerns, or if it is a 'life event' evoking more psychological concerns?"

Finally, the importance of the nurses in assessing spiritual needs was emphasized by the participants. Physicians discussed how the nurses' information was helpful in addressing spiritual needs and in assessing the potential benefit of asking the spiritual counselor to visit the resident.

"I see issues come up [in a nursing home resident] and think: what is this? And if you want an answer to a question like that, you will find it through the nurses, they will tell you why this resident does not want anything, does not do anything. When I wonder what is the matter, has she gone through a lot in recent years, and then I find a way to address the issue [through the nurses' information]."

C. Spiritual caregiving in residents with dementia

In all three focus group discussions the participants addressed the topic of spiritual caregiving in residents with dementia, including advanced dementia. Consequently, the impossibility of (verbal) communication with these residents was perceived as a barrier to the assessment of spiritual needs. In fact one participant stated that:

"Being able to verbally communicate about it [spirituality] is a prerequisite... for me."

Communication with the family on spiritual or religious matters instead was nevertheless not mentioned.

Religious rituals were considered an accessible and supportive way to satisfy certain spiritual needs of people with dementia, as one participant explains:

"Shortly before death, at the bedside, simply saying 'The Lord's Prayer' and a 'Hail Mary' is often quite calming."

Participants from the south of the Netherlands in particular emphasized the importance of rituals, such as attending mass and singing canticles, as one participant states:

"When you would go to mass on a Sunday morning and observe how they [the residents with dementia] respond, you will find that many people experience the ritual of the mass as very special, it calms them. Then you realize that it still plays an important role. It is also the music that appeals to them, that they still recognize. Even if they cannot talk anymore, they sing along anyway."

Also, religious artefacts were considered to be helpful in communicating with residents about their spiritual needs, and to assess whether a spiritual counselor can help to relieve spiritual needs, specifically in residents with dementia. This, again, was put forward especially by participants from the South of the Netherlands, where these objects are an integral part of the Catholic religion. These would include images of Christ and the Virgin Mary, or pins and medallions with images of saints. Participants viewed these religious objects as indicators of the resident's spirituality, making it easier to start a conversation on their spirituality/religious beliefs.

"When you look around you might see a little statue of the Virgin Mary, yes, when you look around the bed you can see things like a medallion [with an image of a saint], for protection. This used to be pinned to their clothing. So these are all things you pay attention to, things that tell you that someone is religious."

D. Cultural and generational differences

Participants mentioned cultural differences between the Northern and Southern part of the Netherlands. One of the participants stated:

"I worked in the South[ern part of the Netherlands] for a while, and of course the spiritual counselor was incredibly important there, even more important than the doctor in daily life."

Physicians from the (primarily Roman Catholic oriented) Southern part of the Netherlands described religious and other spiritual issues more vividly and also directly or indirectly related them to the Roman Catholic faith. The role of the spiritual counselor would be prominent in the discussions. Some physicians provided examples of how spiritual counselors had been a barrier to adequate spiritual caregiving, because of negative associations with the Roman Catholic Church.

"We had G. here [an orthodox Roman Catholic bishop in the South of the Netherlands], who was very strict and estranged many people from the Catholic Church. And some people developed a really strong aversion to the church and religion. (...) And when you offer to send a spiritual counselor a huge wave of negativity comes out."

In addition, one participant pointed to a potential generation gap between residents and nurses, as most of them were born in an era of secularization, a process that took place in the Netherlands in the 1960s and '70s, which seems more prominent than the generation gap between (older) physicians and residents.

“I have been an atheist for 30 years now, and for me religion is no longer relevant. On the other hand: I am usually the one who brings up the last sacraments, not the nurses, because they have no idea anymore what the inside of a church looks like.”

Also, as younger residents were not thought to be very familiar with old religious rituals, participants described how younger residents in hospice units in nursing homes developed their own set of rituals, as one participant pointed out:

“...Nowadays there is also a younger generation of residents who are going to die, who organize this differently, gathering everybody together for a last time, and letters are read out loud, or passed on to the children. They often refer to matters that are difficult for the people involved to talk about. Or a farewell gift is presented, and afterwards they share a meal together, for example...”

DISCUSSION

The aim of our study was to explore how Dutch elderly care physicians perceive spirituality, how they view their role in spiritual caregiving at the end of life and to identify barriers and facilitators in spiritual caregiving at the end of life in nursing homes. To the best of our knowledge this is the first study on spiritual caregiving amongst physicians practicing in nursing homes, and one of the very few studies that addresses spiritual caregiving in dementia at the end of life.

Addressing spirituality at the end of life and spiritual care

The physicians' spontaneously expressed concept of spirituality at the end of life mostly concerned religious aspects, but after further reflection they mentioned a wide variety of elements related to spiritual well-being, such as being at peace, harmony, trust in an afterlife, meaning, acceptance of death and completion of life. These are all considered to be important aspects of spirituality at the end of life, and concord with recently published concepts of spirituality at the end of life.^{3,15,16,17}

The participants expressed a wide range of perceptions toward their role in assessing spiritual needs and in the provision of spiritual care in nursing home residents at the end of life. Not all participants considered paying attention to residents' spiritual issues their concern. A recent US survey among oncology nurses and physicians in academic centers also showed that the physicians did not always consider spiritual care as a part of their professional role, and that training in spiritual caregiving is critical to the provision of spiritual care.¹⁸

Potential barriers are not always context dependent, as those that were voiced by the participants in our study, such as the lack of time and lack of confidence in assessing and addressing spiritual issues in residents at the end of life, were also identified by Chibnall et al.⁷ in a group study in the US with physicians practicing in hospitals, and by Grant¹⁹ in

a study with general practitioners. Despite the participants' vast experience in end of life care for multiple patients each year and their training in elderly care medicine compared to these studies, the perceived barriers were highly similar. However, although the three-year vocational training of an elderly care physician in the Netherlands includes a curriculum on palliative care,²⁰ it does not include specific training in assessing spiritual needs and providing spiritual care, which might explain the lack of confidence in assessing and addressing spiritual issues. Several studies underline the importance of specific training in assessing and providing spiritual care,^{21,22} and training in spiritual care is seen as critical to the provision of spiritual care.¹⁸ International studies^{3,23} and the Dutch guideline on spiritual caregiving¹⁵ may provide a first stepping stone in developing training programs for physicians when discussing spiritual and religious concerns with their patients.

Communication and collaboration on spiritual care

In this study, the physicians described how their own spirituality was sometimes supportive of, but could also be a barrier to communication with nursing home residents on spirituality. We found (by relating the participants' contributions to their characteristics) that participants who had distanced themselves from their religious upbringing felt more confident in discussing religious and spiritual issues with residents, possibly because they were more familiar with reflecting on these issues.

The nurses' role (i.e. providing information) was considered to be crucial to spiritual caregiving. This finding concurs with a US study with nursing home residents by Wallace & O'Shea,²⁴ and was also observed in a previous ethnographic study that we conducted in a Dutch nursing home as part of a larger project on spiritual care at the end of life in Dutch nursing homes.²⁵

Even though multidisciplinary communication and collaboration is often promoted with regard to spiritual care,^{3,15} participants in our study described collaboration with the spiritual counselor as complex, because of an experienced tension between the spiritual counselors' professional confidentiality and openness in multidisciplinary collaboration. This tension is reflected in the professional standard for Dutch spiritual counselors in healthcare. On the one hand, spiritual counselors are supposed to “contribute to individual plans for care, nursing and treatment”, ...work with other caregivers and engage in formal and informal consultation”, which implies multidisciplinary collaboration. On the other hand emphasis is laid on ‘the sanctuary function’, which implies that a patient can at all times call upon a spiritual caregiver separate from other caregivers, and spiritual caregivers have the right to visit patients at their own initiative. In the professional standard, this sanctuary function of the spiritual counselor including their professional confidentiality should be balanced with multidisciplinary collaboration.²⁶ However, no recommendations on how to do this are mentioned. Further research is needed to explore if this sanctuary function of the spiritual counselor, including professional confidentiality, is interpreted differently by different spiritual counselors, and how this aspect of their professional standard could be best balanced with multidisciplinary collaboration.

The place of religion in spiritual care

In this study, participants mentioned how the residents' religious conviction/background was not always supportive towards their spiritual wellbeing, and a spiritual counsellor might even evoke negative associations in the nursing home resident. But they also de-

scribed how religious artefacts were helpful in spiritual caregiving and how religious rituals supported residents in their spiritual wellbeing. Therefore, asking the resident about the meaning of their religion and the church could provide important information to start a conversation on spiritual issues and for appropriate spiritual care giving, which is in line with a more sustained and coherent approach to developing spiritual and cultural care knowledge and practice.²⁷

In addition, participants described how (especially younger) nursing home residents in the Netherlands organize a more secular type of spiritual care, by creating their own rituals with their loved ones. This was specifically mentioned by participants in the South of the Netherlands, which is predominantly Roman Catholic. The Roman Catholic tradition has many spiritual artefacts, such as statues of Christ, the Virgin Mary, rosaries etc. These artefacts were also considered by the participants to facilitate the assessment of spiritual needs and providing spiritual care. It also has rich rituals, such as attending mass and the Stations of the Cross. According to Wojtkowiak,²⁸ humans create and perform rituals in dealing with death and dying, which provide us with symbolic actions that have meaning and help us deal with the transition from life to death. In a secular society, elements of old rituals can be re-used or re-interpreted, or may be re-invented. Wojtkowiak also showed that these personal forms of meaning making are more frequently used in Roman Catholics and people with no religious affiliation than in Protestants.²⁹ Other international studies show that these rituals are mostly rooted in specific religious traditions.^{30,31}

Spiritual care and dementia

Assessing spiritual needs and providing spiritual care in residents suffering from (advanced) dementia was considered difficult because of the difficulty of (verbal) communication with the residents with dementia. In such cases, performing religious rituals and using spiritual artefacts could facilitate the assessment of spiritual needs and could contribute to spiritual wellbeing in residents with dementia at the end of life. Similar examples were described in an essay by Buckwalter,³² in which she promotes religious rituals as spiritual support, even in people with profound memory loss. Another way of (pre-emptively) overcoming potential communication barriers when assessing spiritual needs in people with (milder forms of) dementia is through organizing “spiritual reminiscence” sessions, i.e. small group sessions where residents with dementia discuss spiritual themes, e.g. meaning in life and vulnerability and transcendence (MacKinlay and Trivett)³³. However, it is unknown whether this would work for people with advanced dementia.

Strengths and limitations

To the best of our knowledge this is the first study on spiritual caregiving amongst physicians practicing in nursing homes, and one of the very few studies that addresses spiritual caregiving in dementia at the end of life. We consider our research methods as a strength, with the use of an experienced moderator and the investigator triangulation in collecting and analyzing the data. As we focused on the physicians’ perspective on spirituality and spiritual care, we did not include the perspective of nursing home residents, spiritual counsellors, psychologists and nurses in this study. Although the selection of the participants was purposeful and many characteristics of physicians were taken into account, there still may have been selection bias that influenced the results. Nevertheless,

we are of the opinion that the perspectives we describe are tenable amongst other elderly care physicians and provide valuable insight in the gaps that need to be closed in order to provide high-quality spiritual end of life care in residential care. This, however, is an issue that warrants further study. As Chochinov & Cann³⁴ recommend, research on spirituality should ultimately involve a broad range of international constituencies.

CONCLUSION

In sum, this study shows that the physicians’ perception of spirituality at the end of life comprises religious aspects as well as aspects that are defined as spiritual wellbeing in literature. Participants had a very diverse perception of their role in assessing spiritual needs and providing spiritual care, and lack of experience, training and time were mentioned as a barrier. Specific training programs in addressing nursing home residents’ spiritual issues may be developed for elderly care physicians. Collaboration with the spiritual counselor was challenging, because of the perceived tension between professional confidentiality and multidisciplinary collaboration in spiritual counsellors. Further study is needed to explore how spiritual counsellors can balance their professional confidentiality with multidisciplinary collaboration. Spiritual care in dementia was considered difficult because of the inability to verbally communicate. Religious rituals, artefacts, music and spiritual reminiscence may help nursing home residents with dementia to experience spirituality at the end of life.

Further research is also needed to study if specific training may support elderly care physicians in assessing and addressing spiritual needs, and on best practices in providing multidisciplinary spiritual care at the end of life in nursing home residents, including residents with dementia, preferably in cross-national work.

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Description of authors’ roles

The study was designed by: Marie-José H.E. Gijsberts, Jenny T. van der Steen, Martien T. Muller, Michael A. Echteld, Luc Deliens; the data were collected by Marie-José H.E. Gijsberts, Jenny T. van der Steen, Martien T. Muller and Michael A. Echteld. The data were analysed and interpreted by all authors. All authors approved the submitted paper. Drafting of the manuscript by Marie-José H.E. Gijsberts.

Table 1: Participant characteristics

	Total	Focus group 1	Focus group 2	Focus group 3
Demographics				
Male	7	2	2	3
Female	11	4	4	3
Age, range (years)	30 – 65	35 – 56	30 – 55	34 – 65
Working experience, range (years)	6 - 37	8 – 22	6 – 30	10 – 37
Professional Experience and Interests (more possible)				
Hospice Unit	7	1	4	2
Stroke Rehabilitation	10	6	2	2
Residents suffering from Dementia	14	4	6	4
Residents suffering from Physical Disabilities	11	4	4	3
Additional Training Palliative Care				
Yes	7	1	3	3
No	11	5	3	3
Personal Religious Beliefs:				
Raised /Current				
Roman Catholic	11/ 2	2 / 2	4 / 0	5 / 0
Protestant	1 / 0	1 / 0	0 / 0	0 / 0
Jewish	1 / 0	1 / 0	0 / 0	0 / 0
Anthroposophic	1 / 1	0 / 0	0 / 1	1 / 0
Buddhist	0 / 1	0 / 0	0 / 0	0 / 1
Humanist	0 / 3	0 / 0	0 / 2	0 / 1
Atheist	2 / 0	0 / 0	2 / 0	0 / 0
Agnostic	2 / 2	2 / 2	0 / 0	0 / 0
Other (Christian)	0 / 2	0 / 0	0 / 1	0 / 1
No specific religious belief	0 / 7	0 / 2	0 / 2	0 / 3
Possible Referral Disciplines in Nursing Home (more possible)				
Spiritual counsellor	18	6	6	6
Psychologist	9	2	4	3
Social worker	4	1	1	2
Nurse specialized in psychiatry	5	3	2	-
Art therapist	2	-	2	-

REFERENCES

1. WHO definition of Palliative Care 2002: <http://www.who.int/cancer/palliative/definition/en/> (Last accessed September 2015).
2. Edwards A, Pang N, et al. The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. *Palliat Med* 2010; 24: 753-770.
3. Puchalski C, Ferrell B, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *J Palliat Med* 2009; 12: 885-904.
4. Bailey ME, Moran S, Graham MM. Creating a spiritual tapestry: nurses' experiences of delivering spiritual care to patients in an Irish hospice. *Int J Palliat Nurs* 2009; 15: 42-48.
5. Hermann CP. (2007). The degree to which spiritual needs of patients near the end of life are met. *Oncol Nurs Forum* 2007; 34: 70-78.
6. Daaleman TP, Williams CS, et al. Spiritual care at the end of life in long-term care. *Med Care* 2008; 46: 85-91.
7. Chibnall JT, Bennett ML, et al. Identifying barriers to psychosocial spiritual care at the end of life: a physician group study. *Am J Hosp Palliat Care* 2004; 21: 419-426.
8. Verenso 2012: Professional standard of elderly care physicians: <http://www.verenso.nl/english/elderly-care-physician-s-field-of-activity/> (Last accessed September 2015).
9. van der Velden LF, Francke AL, Hingstman L, Willems DL. Dying from cancer or other chronic diseases in the Netherlands: ten-year trends derived from death certificate data. *BMC Palliat Care*. 2009 Feb 4;8:4.
10. Bonelli RM, Koenig HG: Mental disorders, religion and spirituality 1990 to 2010: a systematic evidence-based review. *J Relig Health* 2013, 52:657-673.
11. Ennis EM Jr, Kazer MW: The role of spiritual nursing interventions on improved outcomes in older adults with dementia. *Holist Nurs Pract* 2013, 27:106-113.
12. van der Steen JT, Radbruch L, Hertogh CPM, de Boer ME, Hughes JC, Larkin P, Francke AL, Jünger S, Gove D, Firth P, Koopmans RT, Volicer L; on behalf of the European Association for Palliative Care (EAPC): White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* 2014, 28:197-209.
13. Pope C, Van Royen P, Baker R. Qualitative methods in research on healthcare quality. *Qual Saf Health Care* 2002; 11: 148-152.
14. Pope C, Ziebland S, Mays N. Qualitative research in health care: Analyzing qualitative data. *BMJ* 2000; 320: 114-116.
15. Leget C, Staps T, et al. Dutch Guideline Spiritual Care in Palliative Care: <http://www.oncoline.nl/spiritual-care/> (Last accessed September 2015).
16. Gijsberts MJ, Echteld MA, et al. Spirituality at the end of life: conceptualization of measurable aspects-a systematic review. *J Palliat Med* 2011; 14: 852-863.
17. Selman L, Harding R, Gysels M, Speck P, Higginson IJ. The measurement of spirituality in palliative care and the content of tools validated cross-culturally: a systematic review. *J Pain Symptom Manage* 2011 Apr;41(4):728-53.
18. Balboni MJ, Sullivan A, et al. Nurse and physician barriers to spiritual care provision at the end of life. *J Pain Symptom Manage* 2014; 48(3): 400-410.
19. Grant E, Murray SA, et al. Spiritual issues and needs: perspectives from patients with

- advanced cancer and nonmalignant disease. A qualitative study. *Palliat Support Care* 2004; 2(4): 371-378.
20. Hoek JF, Ribbe MW, et al. The specialist training program for nursing home physicians: a new professional challenge. *J Am Med Dir Assoc* 2001; 2: 326-330.
 21. Post SG, Puchalski CM, Larson DB. Physicians and patient spirituality: Professional boundaries, competency, and ethics. *Ann Intern Med* 2000; 132: 578-583.
 22. Nathan Cummings Foundation, Fetzer Institute, George H. Gallup International Institute: *Spiritual beliefs and the dying process: a report on a national survey*. The George H. Gallup International Institute 1997. Princeton Religion and Research Center. Princeton.
 23. Lo B, Ruston D, et al. Working Group on Religious and Spiritual Issues at the End of Life. Discussing religious and spiritual issues at the end of life: a practical guide for physicians. *J Am Med Dir Assoc* 2002; 13: 749-754.
 24. Wallace M, O'Shea E. (2007). Perceptions of spirituality and spiritual care among older nursing home residents at the end of life. *Holist Nurs Pract* 2007; 21: 285-289.
 25. Gijsberts MJ, van der Steen JT, et al. (2013). Spiritual end-of-life care in Dutch nursing homes: an ethnographic study. *J Am Med Dir Assoc* 2013; 14(9): 679-84.
 26. VGVZ. 2002: Professional standard of spiritual counsellors: http://www.vgvz.nl/userfiles/files/Algemene_teksten_website/beroepsstandaard.pdf. (Last accessed December 2014).
 27. Narayanasamy A. The impact of empirical studies of spirituality and culture on nurse education. *J Clin Nurs* 2006; 15: 840-851.
 28. Wojtkowiak J. *I'm dead, therefore I am, the postself and notions of immortality in contemporary Dutch society*. 2011 Nijmegen Radboud Universiteit.
 29. Wojtkowiak J, Rutjens BT, Venbrux E. Meaning Making and Death in a Secular Society: A Dutch Survey Study. *Archive for the Psychology of Religion* 2010; 32(3):363-373.
 30. Cheraghi MA, Payne S, Salsali M. Spiritual aspects of end-of-life care for Muslim patients: experiences from Iran. *Int J Palliat Nurs* 2005; 11(9): 468-74.
 31. Prosser R, Korman D, Feinstein RA. An orthodox perspective of the Jewish end-of-life experience. *Home Healthc Nurse* 2012; 30(10): 579-585.
 32. Buckwalter GL. Addressing the spiritual and religious needs of persons with profound memory loss. *Home Healthcare Nurse* 2003; 21: 20-24.
 33. Mackinlay E, Trevitt C. Living in aged care: using spiritual reminiscence to enhance meaning in life for those with dementia. *Int J Ment Health Nurs* 2010; 19(6): 394-401.
 34. Chochinov HM, Cann BJ. Interventions to enhance the spiritual aspects of dying. *J Pall Med* 2005 8(1): 103-115.

Chapter 4

The practice of spiritual care giving in a Dutch nursing home

an ethnographic study

Spiritual end-of-life care in Dutch nursing homes: an ethnographic study

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ABSTRACT

Objectives

The aim of this study is to explore if and how spiritual needs are assessed and spiritual care is provided to Dutch nursing home residents, including residents suffering from dementia, and if and how caregivers communicate and collaborate regarding the residents' spiritual needs.

Design

Two researchers conducted an ethnographic participatory study in a Dutch nursing home between April 2010 and June 2011, on a psychogeriatric unit (mostly dementia) and a somatic unit for residents suffering from physical disabilities. Inductive thematic analysis was used to identify patterns and trends and to interpret the data.

Results

The physicians did not actively address spiritual issues, nor was it part of the official job of care staff. There was no communication between the physicians and the spiritual counsellor. When a resident was about to die, the nurses started an informal care process aimed at (spiritual) well-being, including cuddling, rituals and music. This was not mentioned in the care plan or the medical chart. The nurses even supported the residents outside their professional role in their spare time. Furthermore, we identified different occupational subcultures, e.g. nurses and physicians, in which behaviour of residents was given different meaning, depending on the frame of reference within the subculture.

Conclusion

Spiritual issues were only addressed informally and were not part of the formal care process, either for residents suffering from dementia or for those with physical disabilities. Our results raise questions about how the lack of communication about spiritual end-of-life care between disciplines, and the informal and formal care processes affect spiritual wellbeing.

INTRODUCTION

In the US, the UK and the Netherlands, about 25% of all deaths occur in the nursing home.^{1,2,3} Palliative care is relevant for many nursing home residents, because they are frail and frequently suffer from life-threatening illness.⁴ Multidisciplinary, team-based palliative approaches focused on relieving discomfort and enhancing quality of life may be appropriate for frail older adults.⁵

Palliative care addresses physical, psychosocial and spiritual problems.^{6,7} In a meta-study of qualitative research, Edwards et al. showed the importance of spirituality and spiritual care in end-of-life care.⁸ Spiritual end-of-life care contributes to quality of life at the end of life, which is the main goal of palliative care.^{9,10} Daaleman et al.¹¹ performed a study on the importance of spiritual care in long-term care settings. They found that spiritual support and care are associated with better overall care at the end of life for long-term care residents, and that the best target for interventions to improve this type of care is the interaction between residents and facility staff. However, the spiritual dimension of palliative care is the least developed and the concept of spirituality is complex.⁷

Palliative care implies a team approach to address the patients' needs.⁶ In Dutch nursing homes palliative care is provided by a multidisciplinary team employed by the nursing home, consisting of specially trained elderly care physicians, nurses, paramedical therapists and psychologists and spiritual counsellors.¹² Research in other settings indicates an important role for nurses in assessing the needs of patients, including spiritual needs.^{7,13,14,15} In the Netherlands elderly care medicine is a separate medical specialty, requiring three years of post-vocational training. Elderly care physicians spend between 50 % and 90%, or even more of their time in the nursing home (Helton et al¹⁶). They have a leading role in the multidisciplinary team approach central to Dutch nursing home care and as such they are responsible for the coordination of the resident's care plan.¹⁷ Despite being optimally positioned to take up this role, a recent focus group study revealed that elderly care physicians did not always feel responsible for spiritual end-of-life care of the residents entrusted to their care.¹⁸ This raises questions about if and how spiritual needs are addressed in practice. To explore this topic we performed an ethnographic study. The aim was to investigate:

1. if and how spiritual needs are assessed and spiritual care is provided to Dutch nursing home residents suffering from dementia or physical disabilities;
2. if and how caregivers, including physicians, nurses, and other staff communicate and collaborate regarding the topic of addressing the residents' spiritual needs;

METHODS

Design

We performed an ethnographic participatory study¹⁹ with data being collected by two researchers – an elderly care physician (MJG) and a social scientist (MTM) – on two units of an urban nursing home: a psychogeriatric unit (mostly dementia) and a somatic unit for residents with mainly physical disabilities. They presented themselves on the unit as researchers. To avoid influencing the practice of spiritual care giving, the goal of the

study was communicated in broad terms, i.e. as focusing on communication between staff members. Therefore the goal of this was covert. Terms related to spirituality were not used to avoid raising awareness regarding spiritual care among the staff. Residents, relatives and personnel were notified of the presence of the researchers by the management of the nursing home. It was agreed with the management that any observed detrimental practice would be reported. The study protocol was approved by the Medical Ethics Committee of the VU University Medical Center, the nursing home management team, and the board representing residents and families.

Setting

MJG and MTM participated as nurse aides on the psychogeriatric unit between April 2010 and December 2010, and continued on the somatic care unit between December 2010 and June 2011. There were 32 residents on the psychogeriatric unit, divided over 2 sub-units, and 26 residents on the somatic unit. The care teams consisted of one team manager (registered nurse), 10 certified nurse assistants, 5 nurse assistants in training, 10 nurse aides with different competences and qualifications (all referred to as nurses) and one staff member who directed an activities programme for the residents, e.g. special breakfast projects for a selected group of residents, and light classical music sessions on the unit. A day shift generally consisted of two nurses, one nurse in training, two nurse aides and the activity therapist on 3 days a week. Three elderly care physicians and two general practitioners in training provided the medical care on the two units. The nursing home had an on-staff Roman Catholic spiritual counsellor who provided care to all denominations. MJG and MTM worked as nurse aides alongside the regular nurses on the unit in various shifts, helping the nurses wash and dress the residents and assisting the residents in the bathroom and with eating and drinking. They presented themselves on the unit as researchers. Initially the staff of the units were conscious of the researchers, but their presence and participation in the care giving on the unit soon became routine.

Data collection

Two hundred shifts (a total of approximately 1,600 hours) were spent on the units during the course of the data collection: 180 day shifts, 16 evening shifts and 4 night shifts. MJG and MTM had informal conversations with all persons present on the unit during shifts: residents, relatives, nurses, team managers, physicians, therapists and the spiritual counsellor. We attended formal meetings that were planned and formally recorded in the resident's medical chart and/or care plan, e.g. bedside consultations by the physicians on the unit, meetings with (proxies of) the residents and multidisciplinary team meetings on residents' care planning. In addition, we collected data through informal conversations and from the resident's care plan and care files. Finally, MJG and MTM kept a reflective diary in which they reported their feelings, reflections and interpretations of the observations and conversations. Sometimes the conversations and observations triggered questions. These were discussed between MJG and MTM on a regular basis and were followed by additional formal interviews if it was thought this would help explain/deepen/enrich the observations. Thus eleven formal interviews were held with nurses (4), physicians (3), spiritual counsellor (1), residents (2), and a resident's proxy (1). All interviews were recorded and transcribed verbatim. In sum the data sources are: observations, informal conversations and formal meetings, additional formal interviews and information from the resident's care plan.

Analysis

To identify patterns and trends in the data, and to interpret the data, we used inductive thematic analysis. There were no pre-conceived themes; all themes emerged from the data.²⁰ Data triangulation was used to ensure consistency and we searched for convergence among the different sources of data to discover themes²¹. MJG and MTM compared their field notes and reflective diaries concerning the two sub-units of the psychogeriatric unit every two weeks. The field notes and reflective diaries were independently read and re-read by MJG and MTM who performed the fieldwork, after which fieldnotes and reflective diary were compared and analysed for differences and similarities. Field notes and interview transcripts were initially coded using open codes based on the words used by MJG and MTM in the field notes or by the participants in their interviews. Interim reports were discussed with other members of the research group. As a starting point for the present study 'sensitizing concepts' were used as a general sense of reference and guidance which entailed the following broad notion of spiritual care that comprises elements similar to other recently published definitions^{7,22} and is derived from our earlier conducted systematic review on spirituality at the end of life²³:

1. Spirituality encompasses three dimensions: Spiritual Wellbeing, Spiritual Coping, and Spiritual Cognitive Behavioural Context (which in turn includes Spiritual Beliefs, Spiritual Activities, and Spiritual Relationships).
2. Spiritual Wellbeing comprises several aspects, including peacefulness, completion of life, and a sense of purpose and meaning. Spiritual Wellbeing can be seen as an outcome of spiritual care.
3. Spiritual Coping, as well as the Spiritual Context (Spiritual Beliefs, Activities, and Relationships) may contribute to Spiritual Wellbeing.

After the observations on the psychogeriatric unit, we continued on a unit for residents with physical disabilities. Our aim was to compare the findings in both units, and to explore whether any difference between the residents' disabilities was perhaps reflected in a different approach towards spiritual caregiving at the end of life.

RESULTS

The themes that emerged from our study were:

- Formal spiritual end-of-life caregiving
- The informal end-of-life care process
- Spiritual end-of-life caregiving on the psychogeriatric unit and the somatic unit
- Distinguishing psychosocial and spiritual aspects of caregiving
- Occupational subcultures within the nursing home

Formal spiritual end-of-life caregiving

During our study a total of fourteen residents passed away on the two units. We found that the physician was called for bedside consultations when the resident was ill or when the nurses observed signs of discomfort, such as pain, anxiety, or challenging behaviour,

or when they observed a general decline in the residents' health condition. These cases were also discussed in multidisciplinary meetings or in meetings with residents and their families. Spiritual needs were not mentioned in the care plan and were not discussed with residents during bedside consultation or in multidisciplinary meetings. Spiritual needs and spiritual care were never a topic.

We interviewed the elderly care physicians responsible for the residents on the units where we conducted the observations and invited them to talk about their perceptions and practice of addressing the residents' spirituality or their spiritual needs. They confirmed that they did not actively address spiritual issues such as spiritual beliefs or spiritual needs at the end of life, as the following quotations from interviews with three of the physicians demonstrate:

'I never really asked [about spiritual needs], sometimes I ask: are you afraid of dying? But I don't ask it at the end of life, but at an earlier stage.'

Interview physician 1

'I hesitate to bring it up, because I am afraid to impose something [the physician's own spirituality] on the resident or that they will take it the wrong way.'

Interview physician 2

'I think you have to be very cautious, and you must be very clear about what you can or cannot bring up in a conversation like that.'

Interview Physician 3

When asked about how discussing spiritual issues could be facilitated, one of the physicians referred to additional training and guidelines.

'I would like to do it [address spiritual issues], but I would need additional training on how you address these issues, or what kind of questions I could ask the resident, because based on my own spiritual beliefs I have certain ideas about the topic, but that's not the way to address them, you see. Everyone has his own spiritual path, so guidelines are needed, because I cannot address these issues based on my own spirituality.'

Interview physician 2

We did not observe any formal communication between the physician or any of the nurses and the available on-staff spiritual counsellor. However, we did observe the spiritual counsellor in action several times. She was on the unit after one of the male nurses died unexpectedly, which had a great impact on the other nurses. We also witnessed her holding special religious services for residents suffering from dementia. Several times we found that her presence invited ad hoc requests by nurses or physicians to see a resident. An interview with her confirmed that she intentionally presented herself and her expertise informally in this way.

"When I am visible [to nurses and physicians] they will notice me and maybe think

of a resident who might need me. Recently a nurse on the psychogeriatric unit spoke to me informally, saying 'Good to see you, Mrs V recently told me she wanted to talk to a priest'. The weeks before I had visited this unit more often, that may have made them think 'Maybe we should talk to her' when they see me'".

Interview spiritual counsellor.

The informal end-of-life care process

The deaths of the fourteen residents during our study were mostly preceded by a gradual deterioration of their health, which required more frequent bedside consultations by the physician. When a resident was close to death, we observed that the nurses started an informal care process that was not initiated or arranged by the physician, nor was it mentioned in the care plan. In all cases we found that, after one of these consultations, the nurses discussed the situation of the resident and their loved ones among themselves during their break: should they call the relatives, should the resident be taken to the special room on the unit where they provided special care for residents for whom death was imminent?

'This also happened to Mrs J, one of the residents of the psychogeriatric unit. She had problems with eating and drinking, and had lost a lot of weight. Otherwise she was comfortable: there were no signs of pain or fear, there was no skin breakdown. After the physician's bedside consultation that morning, everyone agreed that it would not be very long before she passed away, and she was brought to the special room on the unit. The nurses spoke in low voices, carefully rearranged the flowers on a little table and put on Mrs J's favourite classical music. The small essential oil burner filled the room with the scent of lavender. They left the room, leaving the door ajar so any sign of discomfort would reach them quickly. At least every half hour they checked on her during that busy shift, adjusting tone, mood and loudness of their voices. On a previous occasion I noticed that an extra bed was brought into this room for the relatives, so they could comfortably stay the night. Relatives were served meals and sometimes were encouraged to have a time-out, or sit with the resident in 'shifts' when they were getting too tired'.

Reflective diary

This attention exceeds the treatment of psychosocial and physical symptoms, such as anxiety, pain or shortness of breath. Much attention was given to supporting the relatives so they could experience their connectedness to the resident these final hours, accept the imminent death of their loved one and let go. After observing these informal care processes a few times, we asked one of the experienced nurses to describe the way she provided end-of-life care to the residents and their loved ones during the final days.

"I was having my coffee break and I said: 'I have a strange feeling about this man. I saw something in his eyes, I thought: something is wrong, and I told my colleagues: 'I am going to mister K now to help him, but I want to talk to him first. I will let you know when I am ready'.

I stood beside his bed and said: 'Listen, is there something you want to get off your

chest?' He looked at me, and I held his hand, and said: 'You know where it's at, you are increasingly short of breath. I said: 'Is there anything you need?' You know, the way you should ask these things, very straightforward. I said: 'is there anyone?' And yes, he said: 'my son.'

His care file said that his son was only to be notified after he passed away. His daughter, too. And when my shift was almost finished I went to see him, he looked at me with tears in his eyes and I knew that I would not see him again. I was so glad that he had expressed his last wish. At the end of my shift I tried to call his son, but the number was out of order. Finally, with the help of someone else, they reached his son, and when I came back on the unit a few days later I heard his son had sat beside his bed that night, and I thought: 'thank God, he must have passed away peacefully'."

Interview nurse B.

This case shows how nurses also want to mediate between family and the resident, for the resident to be at peace when he or she dies and to accept the way relationships with loved ones have developed, to achieve closure.

We observed many nurses meet needs of the residents outside their professional role. This included shopping for residents, but also taking them out to important events, such as weddings or funerals of loved ones, in their spare time. In many instances we also found that this involvement had a personal significance for the nurses.

Nurse M, an elderly woman originally from South America, decided to take Mrs P to the wedding of her daughter. She knew that her daughter's partner had insisted on marrying sooner than originally planned, because Mrs P's dementia was progressing, and she was eating less and less, in spite of the nurses frequently offering and urging and despite the fact that she was offered food that she especially liked. When her daughter visited Mrs P on the unit and discussed the new wedding date, she started to cry and said that she couldn't find anyone to accompany her mother to the wedding. The daughter had said explicitly that her wedding and her mother's attendance signified the completion of their relationship to her.

Reflective diary

In an interview regarding this event the nurse in question expressed why she accompanied the resident and what this meant to her personally.

For me this all was very meaningful, how shall I put it: death is part of life. At a certain age you pass away. So the moment I saw the daughter in tears when she said: 'I have no one to escort my mother to my wedding, what am I to do?' I thought: 'I cannot leave it at this, and I said: I will escort your mother to your wedding.'

Interview nurse M.

Spiritual end-of-life caregiving on the psychogeriatric unit and the somatic unit

After the observation period on the psychogeriatric unit we continued our study on the somatic unit for residents with mainly physical disabilities. Obviously some residents of the psychogeriatric unit could no longer verbally express their needs and wishes at the end of life, but others were still able to indicate their wishes with the help of their relatives and the nurses. We discovered that many residents with mainly physical disabilities also needed the support of loved ones and nurses to express their needs. The caregiving goals of the nurses appeared to be the same, and the individual residents were approached and comforted in a way that was appropriate for their cognitive status, but otherwise very similar.

One of the residents on the somatic unit for residents with mainly physical disabilities who died during our study was Mrs G. She was an artist and had recently had her last exhibition. She was 79, and suffered from rheumatoid arthritis and terminal heart failure. She had had surgery for ovarian cancer, and had had no symptoms in the past years. Recently she had suffered severe vaginal bleeding. Her gynaecologist was contacted, there were no more curative options. She was feeling progressively weak due to the blood loss. She had an appointment with the cardiologist regarding aortic valve replacement, and discussed with the physician that she considered not having the operation, because her gynaecological problems were becoming more serious than her heart condition. She asked to talk to her ex-husband, her two sons, the team manager and the physician. She mentioned that her recent exhibition had completed her life and that she was very grateful to her ex-husband and sons that they had participated in organizing it.

The following weeks she became visibly weaker. Another family meeting was arranged. One of the nurses sat close to her son, who suffered from schizophrenia, to support him if necessary. She explained to him that his mother was very ill now, and that she would not live much longer and that she would have to let him go soon. He was very tense and seemed to struggle to find arguments to counter what she said but couldn't find them. They were left alone to say their goodbyes. Later on I saw her son with a nurse who was comforting him, he was sad, but not as tense as before. The nurses treated Mrs G's pain, comforted and supported her in the process of letting go. She died the next morning.

Reflective diary

We observed no significant difference between the psychogeriatric unit and the somatic unit regarding this process of end-of-life caregiving by the nurses, in which a peaceful death and completion between loved ones were essential spiritual caregiving goals. As for the example of Mrs G: she was still able to initiate and participate more actively in this process of completion, but the nurses' approach of the resident and their comforting of the relatives was essentially the same. We wanted to know whether the nurses agreed with us. In informal talks during coffee breaks they confirmed our observation. In a formal interview nurse B underlined it.

“Basically it makes no difference to me whether a resident is suffering from dementia or not. Maybe a resident with dementia doesn’t understand things the same way, for instance when you tell them that they will get a little morphine. In my experience most residents who are going to die soon have a very clear mind, even in dementia. Maybe I give residents with dementia that little bit extra, for instance when someone loved a certain scent or music, a hug, but basically it doesn’t make any difference to me, every individual deserves as much as another, depending on the situation. Sometimes residents need a little support to let go, residents with dementia too. There was this woman [suffering from dementia], she was so tense, we did not know what was bothering her, I went up to her and said: ‘Look, you are making it so much harder for yourself, maybe you don’t feel that you are ready to die, but I don’t think that this is what you want either, so try to let go.’ And shortly after that I saw her relax completely, like she was finally ready.”

Interview nurse B

Distinguishing psychosocial and spiritual aspects of caregiving

As the quotations show, the psychosocial and spiritual aspects of caregiving are distinct but not separate: Mrs G’s concerns about her son, for instance, had an emotional and social aspect, but her intention was also to complete her significant relationships at the end of her life. The exhibition of her artwork that her family had organized for her was a social gesture, but also a contribution to the completion of her life, as she stated. A similar distinction can be made in the relationship between Mr K and his son.

Occupational subcultures within the nursing home

The communication between nurses about their observations of the residents’ behaviour and the meaning they attached to this behaviour was different from the communication between nurses and physicians. The case below illustrates how the nurses’ perceptions of a patient’s desire not to live anymore was communicated to the physician in terms of a medical problem.

Mrs R. was a resident on the psychogeriatric unit. She had severe dementia. She lay in bed, or sat in the unit’s living room in her customized wheelchair. During our study we noticed that she became increasingly fatigued and tense when she was being dressed. Assisting her at mealtimes was also getting more and more challenging and at some point she no longer ate and drank sufficiently. Nurse I. said: “I last saw Mrs R about a week ago. She basically sits or lies with her mouth open all day, and this makes it easy to put the food in her mouth when you assist her with her meal. After the meal she often brings up the food or coughs, especially when her daughter has helped her. But now she starts retching and bringing up food after only a few spoonfuls. I think this is the only way she can show us if she wants to eat or not, this retching and heaving is the only way she can express that she is ready to die, to express her wish: no more. I think it is best to stop offering her food when she retches, to respect this wish.”

This was also discussed during the nurses’ breaks: Mrs R wants to show us she doesn’t want to live anymore, and this is the only way she can express her wish. Later that day

the on-staff physician visits Mrs R for a bedside consultation and talks with the nurses about recent developments. To my astonishment Nurse I introduces this development as a swallowing problem. The physician diagnoses the problem as ‘swallowing problem in the context of progression of dementia’ and records this in her medical chart. Later that day in a meeting with the daughter of Mrs R the problem of retching and heaving is presented by the physician as a ‘swallowing problem due to the progression of dementia.’

Reflective diary

Among themselves the nurses discussed and labelled observations regarding residents and their care problems and behaviour differently, as compared to when they were talking to the physician during bedside consultations. Mrs R’s wish not to live anymore changed into a swallowing problem. We found there were occupational subcultures within the nursing home, related to the different professions, in which behaviour of residents was given different meaning, depending on the frame of reference within the occupational subculture, i.e. nurses and physicians. This was observed several times in situations with other residents.

DISCUSSION

We explored how spiritual needs are assessed and spiritual care is provided to Dutch nursing home residents by multidisciplinary teams, and if and how caregivers, including physicians, nurses, and other staff communicate and collaborate in addressing the residents’ spiritual needs. To focus our observations we started from sensitizing concepts derived from our earlier systematic review which resulted in a global conceptual framework.²³

We did not observe any formal spiritual end-of-life caregiving during our study, such as communication between the physician and the spiritual counsellor on spiritual needs of the resident or a mention of spiritual needs in the care plan. The spiritual counsellor chose to present herself on the units in an informal way, which may have contributed to the informal spiritual end-of-life caregiving, but it may also have impeded formal communication with nurses or physicians on spiritual needs. In interviews we asked the physicians what they needed to facilitate the assessment of spiritual needs and spiritual caregiving. One of the physicians referred to the need for additional training and guidelines as part of their vocational training to become an elderly care physician. In our focus group study¹⁸ this was also underlined by the participating elderly care physicians. The vocational training for elderly care physicians includes a curriculum on end-of-life care, but it does not address the assessment of spiritual needs or (the coordination of) spiritual caregiving.

We did observe many informal examples of spiritual end-of-life care. The goal of these informal care-giving activities appeared to be to help the resident die peacefully, to complete their life and their relationships with loved ones. Based on our systematic review²³ we developed a model on spirituality at the end of life that captures these aspects in the dimension Spiritual Well-Being, which is the outcome of spiritual caregiving. According to this concept of spirituality the nurses provided spiritual care by helping the resident to complete her life (Mrs P); to emphasize the purpose and meaning of life (Mrs G); to die at peace with loved ones (Mr K); and by providing spiritual activities that contribute to spiritual wellbeing (Mrs J).

The nurses even supported the residents in completing meaningful relationships with loved ones outside their professional role. We label these initiatives as informal care, because these issues were addressed by the nurses on their own initiative and were not discussed in formal meetings such as multidisciplinary team discussions. The spiritual counsellor may also contribute to spiritual wellbeing at the end of life by turning to spiritual resources, e.g. spiritual beliefs and spiritual activities, such as praying or meditating, and by relating to the resident on a spiritual level. These aspects of spiritual caregiving at the end of life were not observed during our study.

No major differences were found between the psychogeriatric unit and the somatic unit. We observed the same informal resident-oriented spiritual care activities. In this respect, our findings are in line with those observed by The and colleagues in a similar setting.²⁴ The nurses confirmed this resident-oriented approach in informal discussions during coffee breaks, during our observations and in a formal interview. Many physical progressive and chronic diseases also involve cognitive impairment, e.g. stroke, Parkinson's disease, and Multiple Sclerosis. This may partly explain why nurses employed similar strategies in their approach of residents suffering from dementia and residents with physical disabilities. Furthermore, the resident-oriented caregiving seemed to be tailored to the specific cognitive possibilities and spiritual needs of the individual resident. For the nurses, residents and relatives, moving a resident to the 'special room' symbolized that a resident would die soon. This move denoted the last stage of the resident's life and signalled the need to support each other (nurses, relatives and sometimes the resident) in sadness and joint preparation for the death of the resident.

In several situations we could distinguish psychosocial and spiritual aspects in the patients' needs. The nurses and physicians did not make this distinction. In her study MacKinlay²⁵ also found that 'there is an overlap between psychological and spiritual dimensions', and that 'spiritual needs assessed and diagnosed as psychosocial will not be met by appropriate strategies.' This differentiation between psychosocial and spiritual aspects should be included in additional training for elderly care physicians.

Spiritual care giving in this particular Dutch nursing home may differ from such care giving in other places and countries. In their comparative study on physician presence in nursing homes for residents with dementia and pneumonia Helton et al.¹⁶ showed that the physicians in Dutch nursing homes spend significantly more practice time in the nursing home than their US counterparts. This means they report significantly more symptoms, know the staff and their capabilities better, are available when a crisis develops and have more opportunity to interact with families. Despite the fact that these are favourable conditions to meet the residents' needs, the physicians did not pay attention to the spiritual needs of their residents.

In our study we found occupational subcultures within the nursing home, with different 'languages' within the subcultures, i.e. the language of the nurses among themselves, and the language between nurses and physicians. In the example of Mrs R, the nurses believed the resident was communicating that she felt her life was completed. They did not want to force her to continue to live by forcing her to eat, and Mrs R was in no position to stand up to them. The nurses discussed this moral dilemma among themselves. However, in their communication with the physician the nurses downplayed their worries, maybe even replaced them by a physical problem – dysphagia–, thus bypassing the discussion and collaboration by nurses and physician on a possible spiritual need. Hertogh and The²⁶ describe a similar example, in which the nurses' experience of the behaviour of the resident also differs from the way the physicians and the psychologists explain this behaviour. It

is important that physicians are aware of these different occupational subcultures within the nursing home and the frames of reference and 'languages' that define them. These different frames of reference may make it difficult to communicate and fully address every dimension of a symptom.

We found the nurses to be adequate in supporting the residents and their loved ones and in meeting their spiritual needs. According to our concept of spirituality²³ their resident-oriented care supported the spiritual wellbeing of the residents, which is the goal of spiritual caregiving. Their informal caregiving thus complemented the formal care process. Empowering nurses to express their views, observations and experience may help other disciplines within the nursing home understand the importance of their resident-oriented care and enrich the formal multidisciplinary diagnostic and therapeutic approach towards the residents and their loved ones that is outlined in the resident's care plan. Further research to identify facilitating and impeding factors can provide important information to reinforce a resident-oriented approach, with respect and kindness towards the resident.

Limitations and generalizability

This study was performed in a single nursing home, situated in the northern part of the Netherlands. In a previous focus group study¹⁸ we identified cultural differences between the participating physicians in the northern and southern parts of the Netherlands. The Roman Catholic cultural background predominates in the southern part of the Netherlands. The Protestant background, with iconoclasm as part of its cultural heritage, characterizes the northern part. Spirituality seemed to be a more integral part of life and of caregiving in the southern part of the Netherlands: the participants seemed to be more at ease with spiritual issues. These cultural characteristics may have influenced the results of our study. The findings of this study are not generalizable beyond the context of this nursing home in the Northern part of the Netherlands.

CONCLUSIONS AND RECOMMENDATIONS

We found that spiritual issues were only informally addressed by nursing staff and were not translated to the formal care process of residents suffering from dementia as well as residents with only physical disabilities. Our results show occupational subcultures within the nursing home, each subculture using a different language. This raises questions about the communication on spiritual end-of life care between disciplines, and if and how this communication contributes to the spiritual wellbeing of the resident. Informing other disciplines within the nursing home culture of the importance of the informal resident-oriented care by the nurses may enrich the formal multidisciplinary diagnostic and therapeutic approach. The informal resident-oriented care was instrumental to the residents' spiritual wellbeing. Further research is required to determine the best way to reinforce an approach that improves spiritual wellbeing, is resident-oriented, and involves being respectful and kind towards the resident. As the elderly care physicians have a leading role in the multidisciplinary team approach in Dutch nursing home care, examining the educational needs of physicians with regard to spiritual care giving may help develop curricula that address palliative care in all its aspects.

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REFERENCES

1. 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.
2. van der Velden LF, Francke AL, Hingstman L, Willems DL. Dying from cancer or other chronic diseases in the Netherlands: ten-year trends derived from death certificate data. *BMC Palliat Care*. 2009 Feb 4;8:4.
3. Davies S. & Seymour J. (2002) Historical and policy contexts. In: J. Hockley & D. Clark (Eds) *Palliative Care for Older People in Care Homes*, pp. 4–33. Open University Press, Buckingham.
4. Froggatt K, Payne S. A survey of end-of-life care in care homes: issues of definition and practice. *Health Soc Care Community* 2006 Jul;14(4):341-8.
5. Boockvar KS, Meier DE. Palliative care for frail older adults: “there are things I can’t do anymore that I wish I could . . .”. *JAMA* 2006 Nov 8;296(18):2245-53.
6. WHO definition palliative care: <http://www.who.int/cancer/palliative/definition/en/> (Last accessed February 2015).
7. Puchalski C, Ferrell B, Virani R, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *J Palliat Med* 2009 Oct;12(10):885-904.
8. Edwards A, Pang N, Shiu V, Chan C. The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. *Palliat Med* 2010;24(8):753-770.
9. Scobie G, Caddell C. Quality of life at end of life: Spirituality and coping mechanisms in terminally ill patients. *The Internet Journal of Pain, Symptom Control, and Palliative Care* 2005;4(1).
10. Hills J, Paice JA, Cameron JR, Shott S. Spirituality and distress in palliative care consultation. *J Palliat Med* 2005;8(4):782-8.
11. Daaleman TP, Williams CS, Hamilton VL, Zimmerman S. Spiritual care at the end of life in long- term care. *Med Care* 2008 Jan;46(1):85-91.
12. Professional standard Dutch spiritual counsellor: <http://www.vgz.nl/userfiles/files/Professional%20Standard%20Spiritual%20Counsellors%202005.pdf>. (Last accessed February 2015).
13. McSherry W, Cash K, Ross L. Meaning of spirituality: implications for nursing practice. *J Clin Nurs* 2004;13:934-941.
14. Ross L. Spiritual care in nursing: an overview of the research to date. *J Clin Nurs* 2006 15:852-862.
15. Cavendish R, Konecny L, Naradovy L, et al. Patients’ perceptions of spirituality and the nurse as a spiritual care provider. *Holist Nurs Pract* 2006;20:41.
16. Helton MR, Cohen LW, Zimmermann S, et al. The importance of physician presence in nursing homes for residents with dementia and pneumonia. *J Am Med Dir Assoc* 2011 Jan;12(1):68-73.
17. Schols JM, Crebolder HF, van Weel C. Nursing home and nursing home physician: the Dutch experience. *J Am Med Dir Assoc* 2004 May-Jun;5(3):207-12.
18. Gijsberts MJ, van der Steen JT, Muller MT, et al. *Spiritual End-of-life care in nursing homes: An exploratory study among physicians*. Presented at the 15th Congress of the International Psychogeriatric Association (IPA), the Hague, 6-9 September 2011.

- Congress program, page 93. <http://www.ipa-online.org/pdfs/2011congressprogram.pdf>. Accessed February 2, 2013. Full paper is under review.
19. Pope C, Mays N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ* 1995 Jul 1;311(6996): 42-5.
 20. Mays N, Pope C. Assessing quality in qualitative research. *BMJ* 2000 January 1; 320(7226): 50.
 21. Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. *BMJ* 2000 Jan 8;320(7227):114-6.
 22. Selman L, Harding R, Gysels M, et al. The measurement of spirituality in palliative care and the content of tools validated cross-culturally: a systematic review. *J Pain Symptom Manage* 2011 Apr;41(4): 728-53.
 23. Gijsberts MJ, Echteld MA, van der Steen JT, et al. Spirituality at the end of life: conceptualization of measurable aspects-a systematic review. *J Palliat Med* 2011 Jul;14(7):852-63.
 24. The AM. *In Death's Waiting Room, living and Dying with Dementia in a Multicultural Society*. Amsterdam, Amsterdam University Press, September 2011.
 25. MacKinlay E. Understanding the aging process: a developmental perspective of the psychosocial and spiritual dimensions. *Journal of Religious Gerontology* 12;3-4:111-122.
 26. Hertogh CM, The BA. The Loss of a common shared world. Ethical problems in palliative care for people with advanced dementia. *Tijdschr Gerontol Geriatr* 2008 Dec;39(6): 265-72.

Quantitative Research

Chapter 5

Does the spiritual affiliation of nursing homes make a difference in spiritual wellbeing of Dutch nursing home residents with dementia at the end of life?

Dementia end-of-life care in anthroposophic and traditional nursing homes

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ABSTRACT

Context

Every year more than 20,000 people with dementia die in Dutch nursing homes and this number steadily increases. Therefore, the importance of good end-of-life care for these patients including physical, psychosocial and spiritual care is evident. Although the training standards for Dutch nursing home physicians and nurses share a common standard, the philosophy of a nursing home may affect end-of-life care strategies for the residents.

Objectives

To explore if and how the philosophy of a nursing home affects the quality of life and satisfaction with care in nursing home residents suffering from dementia.

Methods

We compared end of life of nursing home residents with dementia in two anthroposophic and two traditional nursing homes in a retrospective study, using the most specific instrument available: the End-of-Life in Dementia scales (EOLD). Family caregivers were invited to complete the EOLD questionnaire after the resident had passed away.

Results

There was no difference in mean Satisfaction With Care scale scores between both types of nursing homes: 32.9 (SD 4.3) and 31.6 (SD 4.9), respectively. The anthroposophic nursing homes had significant higher scores on the 'Symptom Management' (32.9 (SD 7.5) versus 26.9 (SD 9.5)), and 'Comfort Assessment in Dying' scales (34.0 (SD 3.9) versus 30.8 (SD 5.8)) and on its subscale Well Being (7.7 (SD 1.2) versus 6.7 (SD 2.1)).

Discussion

Our results suggest that death with dementia was more favourable in anthroposophic nursing homes than in regular homes. The results inform further prospective studies on nursing homes how this and other philosophies are translated into daily nursing home practice, including decision making in multi-disciplinary teams, family consultation, and complementary non-pharmacological therapies.

INTRODUCTION

In the Netherlands more than 20,000 people admitted to nursing homes with dementia die every year, and their number is still rising.¹ This is why it is important to provide good end-of-life palliative care in nursing homes to this group of patients.

The WHO defines 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.² In recent international literature on palliative care researchers write predominantly about controlling physical and psychosocial problems. The importance of spiritual aspects of the care is increasingly recognized, also in the palliative phase,^{3,4} and also in nursing home residents.⁵ A recent Dutch study on palliative care for (somatic as well as psychogeriatric) nursing home residents shows that care needs are predominantly observed in the psychosocial and spiritual domain, also for nursing home residents with dementia.⁶ Another study, conducted in the United States, demonstrates that spiritual care provided by nursing home staff and providing the opportunity for individual spiritual activities at the end of life of nursing home residents is related to a better evaluation of the care.⁷

In the Netherlands, elderly care physicians, the multidisciplinary team and nursing staff are trained according to the same educational requirements,⁸ creating a common basis for the care to nursing home residents, also in the final phase. Apart from this joint basis for the care the specific spiritual or religious affiliation of a nursing home might create accents that affect the quality of the life and death of the nursing home residents.

In this article we compare the end of life of residents with dementia in anthroposophic nursing homes in the Netherlands with the end of life of residents in traditional nursing homes. Based on the philosophical background (see text box) the spiritual wellbeing of patients is a priority in anthroposophic care. Often non-pharmacological interventions are offered.

Anthroposophic nursing home care

'The anthroposophic view considers the human being to be a unity of body, soul and spirit. Our care focusses all three aspects. Our perspective is that humans continue to spiritually develop up to, or even beyond, the threshold of death.

Next to the usual care provided in the nursing home complementary therapies are offered, such as anthroposophic medication, massage with essential oils, rhythmical massage and therapies such as eurythmy therapy, art therapy and music therapy. The elderly care physician prescribes this complementary care, which is recorded in the patient's care file. The care philosophy is particularly expressed in this additional care, in which the individual needs of the resident are addressed.

Death is considered as a transition to another form of life, a birth into the spiritual world, similar to the birth of the physical individual on earth. We value the process of dying as specifically important and accompany the dying person based on this view.'

Source: Information leaflet Leendert Meeshuis, anthroposophic nursing home.

Our research question in this study is: does the difference in focus of the anthroposophic nursing homes influence the degree of (spiritual) wellbeing and the occurrence of physical and psychological symptoms in nursing home residents in the final months of life?

Anthroposophic nursing homes may perform better with regard to spiritual wellbeing, but a consequence of the specific view on the process of dying (experience it in the highest possible state of awareness) could also be that there is less focus on the immediate alleviation of physical and psychological symptoms. With regard to satisfaction with the provided care we expected families of residents of anthroposophic nursing homes to be more satisfied because the care was likely to meet their expectations to a higher degree.

METHODS

Nursing homes

The only two nursing homes with an anthroposophic affiliation in the Netherlands, located in The Hague and Bilthoven, participated in this study. In addition we approached two 'traditional' nursing homes that both operated on the principle of demand-driven care, in which respect for the resident and linking up with the personal wishes and backgrounds of the resident are key. One of the nursing homes is located in a large city, the other one near the wooded environment of the town of Bilthoven. All nursing homes were willing to participate in the study.

Instrument for end-of-life care in dementia

We utilized the most specific instrument available for the study of end-of-life care in dementia patients, the "End-of-Life in Dementia scales" (EOLD). This instrument was developed in the United States to be used retrospectively by relatives after the death of a resident.^{9,10} The EOLD was translated from English into Dutch by the researchers, and a back translation was prepared by a professional translator and a bi-lingual physician. During the translation process we were in contact with the developer of the instrument, professor L. Volicer, about the exact meaning of some of the items. The EOLD is a questionnaire that consists of three scales, i.e. the "Satisfaction With Care" (SWC) scale, the "Symptom Management" (SM) scale and the "Comfort Assessment in Dying" (CAD) scale.

The SWC scale comprises 10 items with 4 answer categories. The total score of the SWC consists of the sum of the item scores (1 to 4) with a range of 10 to 40, with 40 indicating the highest satisfaction. The SM scale comprises 9 items with 6 answer categories. The total score of the SM is the sum of the item scores (0 to 5) with a range from 0 to 45, with 45 reflecting the least symptom burden. Only 1 of the 9 items is formulated in positive terms: "calm". We view the CAD as an indicator of comfort in the dying process. With the CAD we can calculate scores on four subscales: physical distress, dying symptoms, emotional distress and 'wellbeing'. The subscale wellbeing comprises three items that are found in the literature on spirituality (and in instruments to measure it) as terms that refer to spiritual wellbeing: in particular serenity, but also peace and calm.^{11,12,13} In this way this measurement instrument can give an indication of the physical, psychological and spiritual comfort of the dying nursing home resident. The total score of the CAD comprises the added up item scores and has a range from 14 to 42, with 42 indicating the highest level

of comfort. In all 3 scales negatively formulated items are reverse coded for calculation of item scores and total scores. Several power calculations showed that both groups must consist of 20 residents. We used the Standard Deviation (SD) found for each of the three scales in the development of the instrument (Volicer et al., 2001).⁸ Having a power of 80% and a relevant deviation of 1 SD or 20% of the mean in Volicer's study,^{9,10} Five out of six calculations showed the required minimum number of patients was 20 per group. The power was sufficient for the SWC and CAD on both criteria and for the SM on one of the two criteria (the 20% of mean criterion).

Procedures

Data were collected between November 2005 and July 2007. Every contact person of the residents who died in the participating nursing homes was contacted during that period. Six weeks after the death of a resident of a psychogeriatric nursing home unit the resident's proxy/relative (primary contact person) received a letter from the researcher asking whether he/she was willing to participate in this study. If they consented the EOLD questionnaire, to which had been added several questions about characteristics of the resident and the respondent, was sent to the respondent. 60 contact persons of deceased residents of traditional nursing homes were approached, of whom 34 participated in the study (57%); two contact persons refused and 24 did not respond. Of the 29 contact persons of residents of the anthroposophic nursing homes 20 participated (69%); two contact persons refused and 7 did not respond. Four reminders were sent out to contact persons of anthroposophic nursing homes; one responded. Three reminders were sent out to contact persons of traditional nursing homes; one responded. During the course of the study we stopped sending reminders, to avoid putting too much pressure on the relatives. The nursing staff member who had known the resident well was asked in an interview about the severity of the dementia in the final three months of life, as measured with the Bedford Alzheimer Nursing Severity-Scale (BANS-S).^{14,15} The Medical Ethics Committee of VU University Medical Center approved the protocol and procedures.

Analysis

For a comparison of mean scores between anthroposophic and traditional nursing homes, we used the t-test; the total scores were distributed normally, and distribution of the item scores, apart from a few exceptions - for example "crying", which occurred infrequently - was only slightly skewed. Dichotomous traits were compared using a chi-square test. For the total scores and subscale scores of the CAD we used a significance level of 0.05. Taking into account the large number of comparisons of item scores, a difference in item scores was only considered to be significant at a p-value smaller than 0.01. Missing values did not exceed 7%, except for the item "I would probably have made a different decision if I had had more information", where 20% scored 'not applicable'. For the total calculation, missing items were replaced (imputed) with the item mean of the patient if the maximum did not exceed 2 missing SWC item scores, 3 SM scores, or 4 CAD scores. After imputation no SWC total score was missing, but there were 2 missing total scores for the SM and the CAD, one for each scale and in each type of nursing home.

RESULTS

The mean age of the 20 deceased residents of anthroposophic nursing homes and the 34 deceased residents of traditional nursing homes was very similar (Table 1). In both types of nursing homes the majority of residents were women. There was little difference in severity of dementia and ADL dependency for eating and dressing. The residents in the anthroposophic nursing homes were more mobile than those in the traditional nursing homes: 39% and 63% respectively were completely dependent with regard to walking. In the anthroposophic as well as the traditional nursing homes the respondent was often the child of the deceased resident, and generally female. A total of 55% of respondents in anthroposophic nursing homes were daughters, compared to 29% in the traditional homes ($p=0.063$).

Satisfaction with care

The mean SWC total scores for satisfaction with the care of the anthroposophic and traditional nursing homes were very similar at 32.4 and 31.6 respectively (Table 2). Item scores also did not differ significantly. The least appreciated item in both types of nursing homes was (not) knowing which nursing staff member was working which shift.

Experienced symptoms in final 90 days

The mean SM total score for symptoms of the anthroposophic nursing homes was significantly higher (better) than the score of the traditional nursing homes, i.e. 32.9 and 26.9 respectively ($sp=0.024$) (Table 3). The item score for pressure sores and anxiety were significantly higher in the anthroposophic nursing homes ($p=0.007$ and $p=0.041$ respectively).

All other mean item scores were, although not statistically significant, higher in absolute terms in anthroposophic nursing homes. The item 'resistiveness to care' was an exception, with anthroposophic homes not scoring higher than traditional nursing homes (mean 2.6 versus 3.2 respectively).

Physical, emotional and spiritual condition in the final week

The CAD total score for symptoms and comfort in dying for the anthroposophic nursing home residents was significantly higher than the total score for the traditional nursing home residents (mean 34.0 versus 30.8) ($p=0.021$) (Table 4). Furthermore, the score on the subscale 'wellbeing' was significantly higher in the anthroposophic nursing homes than in the traditional homes ($p=0.042$). The item scores in the anthroposophic nursing homes were systematically, although not significantly, higher, with the exception of one item, i.e. restlessness (mean score 1.8 in anthroposophic nursing homes and 2.0 in traditional nursing homes).

Table 1. Characteristics of Dutch nursing home residents and relatives

	Anthroposophic nursing homes (n = 20)	Traditional nursing homes (n = 34)	p-value
Nursing home residents			
Age at death, mean (SD)	85.0 (6.1)	85.2 (5.8)	0.90
Female, %	85	76	0.45
Severity of dementia (BANS-S score)‡	17.7 (3.8)	19.1 (3.3)	0.20
- Fully dependent for dressing, %	89	83	0.73*
- Fully dependent for walking, %	39	63	0.05*
- Fully dependent for eating, %	39	30	0.85*
Proxy (respondents)			
Female, %	75	53	0.11
Relationship to resident, %			
- Partner	10	12	0.84†
- Son / daughter	70	62	0.54†
- Other	20	26	

*Tested with full range of 4-point scale.

†Partner versus all other. Son / daughter versus all other

‡Bedford Alzheimer Nursing Severity-Scale was 18.6 (SD 3.5) for the total population.
Theoretical range 7-28.

SD= Standard Deviation

Table 2. Satisfaction of relatives with the care provided in the final 90 days preceding death of the residents.

Mean score on the EOLD Satisfaction With Care (SWC) (SD)	Anthroposofic nursing homes (n = 20)	Traditional nursing homes (n = 34)	p-value
SWC total score (SD)*	32.4 (4.3)	31.6 (4.9)	0.51
SWC item scores (SD)†			
1 I felt fully involved in all decision making	3.3 (0.66)	3.4 (0.66)	0.55
2 I would probably have made different decisions if I had had more information	3.3 (0.61)	3.3 (0.65)	0.96
3 All measures were taken to keep my care recipient comfortable	3.5 (0.61)	3.2 (0.62)	0.07
4 The healthcare team was sensitive to my needs and feelings	3.3 (0.57)	3.3 (0.52)	0.83
5 I did not really understand my care recipient's condition *	3.3 (0.73)	3.2 (0.72)	0.61
6 I always knew which doctor or nurse was in charge of my recipient's care	2.8 (0.70)	2.7 (0.87)	0.68
7 I feel that my care recipient got all necessary nursing assistance	3.4 (0.67)	3.2 (0.61)	0.52
8 I felt that all medication issues were clearly explained to me	2.9 (0.66)	3.0 (0.82)	0.74
9 My care recipient received all treatments or interventions that he or she could have benefited from	3.4 (0.59)	3.1 (0.71)	0.17
10 I feel that my care recipient needed better medical care at the end of his or her life	3.3 (0.59)	3.3 (0.74)	1.00

* Possible range: 10 (worst) to 40 (best).

† Possible range: 1 (worst) to 4 (best).

Items were recoded so higher score reflects higher level of satisfaction.

EOLD = End Of Life in Dementia scales.

SD= standard deviation

Table 3. Experience of symptoms in the final 90 days before death according to relatives

Mean scores on the EOLD Symptom Management (SM) (SD)	Anthroposofic nursing homes (n=20)	Traditional nursing homes (n=34)	p-value
SM total score (SD) *	32.9 (7.5)	26.9 (9.5)	0.024
SM item scores (SD) †	observed range: 19-45	observed range: 6-41	
Pain	2.9 (1.9)	2.1 (2.0)	0.12
Shortness of breath	3.7 (1.9)	3.1 (2.0)	0.30
Skin breakdown	4.9 (0.49)	3.9 (1.8)	0.01
Calm	4.5 (0.96)	4.1 (1.5)	0.27
Depression	3.6 (1.5)	2.8 (2.1)	0.12
Fear	3.7 (1.8)	2.6 (2.0)	0.04
Anxiety	3.3 (1.6)	2.4 (1.9)	0.11
Agitation	3.5 (1.7)	2.8 (1.9)	0.21
Resistiveness to care	2.6 (1.5)	3.2 (2.1)	0.29

* Possible range: 0 (worst) to 45 (best).

† Possible range: 0 (worst) to 5 (best). Items were recoded so higher score reflects higher level of satisfaction.

EOLD = End Of Life in Dementia scales. SD= standard deviation

Table 4. Physical, emotional and spiritual condition shortly before death.

Mean scores on the EOLD 'Comfort Assessment in Dying'(CAD) (SD)	Anthroposophic nursing homes (n = 20)	Traditional nursing homes (n=34)	p-value
CAD total score (SD)*	34.0 (3.9) * Observed range: 23-38	30.8 (5.8) Observed range: 18-41	0.021
CAD item scores (SD)†			
1 Discomfort	2.2 (0.63)	2.1 (0.78)	0.58
2 Pain	2.4 (0.75)	2.0 (0.78)	0.12
3 Restlessness	1.8 (0.60)	2.0 (0.74)	0.53
4 Shortness of breath	2.4 (0.75)	1.9 (0.75)	0.03
CAD subscale 1: physical distress‡	8.8 (1.4)	8.0 (2.0)	0.110
5 Choking	2.5 (0.76)	2.4 (0.66)	0.53
6 Gurgling	2.4 (0.75)	2.4 (0.77)	0.83
7 Difficulty swallowing	2.3 (0.87)	1.9 (0.83)	0.10
CAD subscale 2: dying symptoms‡	9.5 (2.4)	8.5 (1.7)	0.082
8 Fear	2.5 (0.61)	2.2 (0.82)	0.22
9 Anxiety	2.4 (0.61)	2.3 (0.73)	0.62
10 Crying	2.8 (0.41)	2.8 (0.41)	0.96
11 moaning	2.5 (0.61)	2.2 (0.78)	0.09
CAD subscale 3: emotional distress‡	10.2 (1.2)	9.5 (2.1)	0.160
12 Serenity	2.5 (0.61)	2.1 (0.78)	0.10
13 Peace	2.6 (0.51)	2.3 (0.80)	0.10
14 Calm	2.6 (0.50)	2.3 (0.74)	0.09
CAD subscale 4: well being‡	7.7 (1.2)	6.7 (2.1)	0.042

*Possible range: 14 (worst) – 42 (best). Items were recoded so higher scores reflect more comfort.

† CAD item scores (SD). Possible range: 1 (worst) – 3 (best). If necessary items were recoded so higher scores reflect more comfort.

‡ CAD subscale 1 comprises the sum of items 1 through 4; subscale 2: items 4 through 7; subscale 3: items 8 through 11; subscale 4: items 12 through 14.

DISCUSSION

Relatives of deceased residents of anthroposophic or traditional nursing homes did not differ in terms of their satisfaction with the care received. In the anthroposophic nursing homes the total symptom burden of residents in the final three months of life was significantly lower than in the traditional homes.

To our knowledge, this pilot is the first study to compare end-of-life care for residents with dementia in traditional nursing homes with the care in anthroposophic nursing homes, as well as the first study in the Netherlands to use the EOLD (End-of-Life in Dementia scales). The population in our studies was small, and the results must therefore be interpreted cautiously, and they need to be confirmed in large-scale studies. However, we also asked the nursing staff to fill in the SM and CAD scales, and we compared their scores with the relatives' scores.¹⁶ The average SM and CAD scores by the nursing staff in the anthroposophic homes were significantly higher than those in the traditional homes. As nursing home residents with dementia at the end of life are generally unable to verbalize their complaints, caregivers have to rely on observations, their own and those of the family. An American study showed that emotional distress was more susceptible to the observer's personal interpretation than physical distress.¹⁷

Our study had a response rate of 61%. In a study of the reliability of mail questionnaires to investigate the satisfaction with the care family members this was found to be an acceptable method, and the maximum response rate with a reminder was 60%.¹⁸

One item showed a significant difference in favour of the anthroposophic nursing homes: they had fewer pressure sores. Mobility of the residents of the anthroposophic nursing homes was also significantly better. We know from the literature that reduced mobility is a risk factor for pressure sores.^{19,20} This might explain the significantly lower occurrence of pressure sores in the anthroposophic homes, but exploratory regression analysis shows it does not really explain the difference.

In the final week before death the symptom burden was systematically (but generally not significantly) lower in the anthroposophic nursing homes. The subscale wellbeing had a significantly better score. These results may be compatible with a philosophy that includes a high degree of acceptance of expressions and emotions of (both somatic and psychogeriatric) residents as found in the descriptions of anthroposophic nursing home care,^{21,22} and that is rooted in the philosophy of life that describes the dying process as a personal farewell to life on earth and a preparation for the next.

Our expectation that reticence with regard to prescribing medication such as opiates and benzodiazepines in anthroposophic nursing homes would negatively impact symptom burden was not confirmed, but this reticence would explain the (non-significant) less favourable scores on the items resistiveness to care (SM) and restlessness (CAD) in the anthroposophic nursing homes. Perhaps the significantly higher score on the subscale wellbeing can be ascribed to the non-pharmacological therapies that are offered during the dying phase, such as external therapy, massage, music therapy and artistic therapies.^{23,24}

The results of this pilot study partially support our initial expectations that the focus of anthroposophic nursing home care can benefit the resident. The results generate questions that can be answered in further large-scale (prospective) research:

1. Are findings the same for care of other religious/spiritual orientations?
2. Which are the effective elements in specific religious/spiritual end-of-life care: atten-

tion for the individual, staff involvement, more attention to high quality of end-of-life care, end-of-life care with a stronger focus on spiritual aspects?

Because the anthroposophic nursing home care is a translation of the spiritual philosophy in the care process - both in the interaction with the residents and in the prescription and application of non-pharmacological treatments - further research will have to clarify the relationship between the philosophy, the decisions in the multidisciplinary consultation, family meetings, the actual care, and the symptom burden. These are some of the focusses of the Dutch prospective "End of Life in Dementia (DEOLD) study."^{25,26,27}

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REFERENCES

1. Ministerie van VWS. *www.brancherapporten.minvws.nl*. 2008.
2. World Health Organisation. *National cancer control program: policies and managerial guidelines*. Geneva: WHO, 2002 (2nd edition).
3. Culliford L. Spirituality and clinical care. *BMJ* 2002; 325: 1434-5.
4. Speck P, Higginson I, Addington-Hall J. Spiritual needs in healthcare. *BMJ* 2004; 329:123-4.
5. Reynolds K, Henderson M, Schulman A, Hanson LC. Needs of the dying in Nursing homes. *J Palliat Med* 2002; 5: 895-901.
6. Brandt HE, van der Steen JT, Ooms ME, Ribbe MW, van der Wal G. The last days of life of nursing home patients with and without dementia assessed with the Palliative care Outcome Scale. *Palliat Med* 2005 jun; 19: 334-42.
7. Daaleman TP, Williams CS, Hamilton VL, Zimmerman S. Spiritual care at the end of life in long term care. *Med Care* 2008 jan; 46 (1):85-91.
8. Besluit Verpleeghuisgeneeskunde: *www.KNMG.artsennet.nl*. 2005.
9. Volicer L, Hurley AC, Blasi ZV. Scales for evaluation of End-of-Life Care in Dementia. *Alzheimer Dis Assoc Disord* 2001 Oct-Dec; 15(4): 194-200.
10. Volicer L, Hurley AC, Blasi ZV. Characteristics of dementia end-of-life care across care settings. *Am J Hosp Palliat Care* 2003; 20: 191-200.
11. 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: 49-58.
12. Underwood LG, Teresi JA. The Daily Spiritual Experience Scale: development, theoretical description, reliability, exploratory factor analysis, and preliminary construct validity using health related data. *Ann Behav Med* 2002; 24: 22-33.
13. WHOQOL SRPB Group (World Health Organisation's Quality of Life Spirituality, Religion and Personal Beliefs Group). A crosscultural study of spirituality, religion and personal beliefs as components of quality of life. *Soc Sci Med* 2005; 08.001.
14. Bellelli G, Frisoni GB, Bianchetti A, Trabucchi M. The Bedford Alzheimer Nursing Severity scale for the severely demented: validation study. *Alzheimer Dis Assoc Disord* 1997; Jun11(2): 71-77.
15. Volicer L, Hurley AC, Lathi DC, Kowall NW. Measurement of severity in advanced Alzheimers disease. *J Gerontol* 1994; 49: M223-6.
16. van der Steen T, Gijsberts MJHE, Knol D, Deliens L, Muller MT. Ratings of symptoms and comfort in dementia patients at the end of life: comparison of nurses and families. *Palliat Med* 2009 Jun;23(4):317-24.
17. Rich SE, Williams CS, Zimmerman S. Concordance of family and staff member reports about end of life in assisted living and nursing homes. *Gerontologist* 2010. Feb;50(1):112-20.
18. Jacoby A, Lecouturier J, Bradshaw C, Lovel T, Eccles M. Feasibility of using postal questionnaires to examine carer satisfaction with palliative care: a methodological assessment. *Palliat Med* 1999; 19: 285-98.
19. Berlowitz DR, Brandeis GH, Morris JN, Ash AS, Anderson JJ, Kader B, Moskowitz MA. Deriving a risk-adjustment model for pressure ulcer development using the Minimum Data Set. *J Am Geriatr Soc* 2001; 49: 866-71.

20. van Marum RJ, Ooms ME, Ribbe MW, van Eyk JT. The Dutch pressure sore assessment score or the Norton scale for identifying at-risk nursing home patients? *Age Aging* 2000; 29: 63-68.
21. van Diggelen MJ. *De psychogeriatrische bewoner in het grensgebied tussen leven en dood*. In: Syllabus symposium Leendert Meeshuis. Bilthoven, 2005: 11-12.
22. de Jong A. *Hospicezorg in het Leendert Meeshuis*. In: Syllabus symposium Leendert Meeshuis. Bilthoven, 2005: 13-16.
23. Busch MEH, Visser AP. *Complementaire zorg*. In: Palliatieve zorg, richtlijnen voor de Praktijk, Utrecht: VIKC, 2006: 91-139.
24. Glöckler M. *De oerbronnen van gezondheid*. Kerk-Avezaath: Centrum voor Sociale Gezondheidszorg, 2003.
25. van der Steen JT, van Soest-Poortvliet MC, Gijsberts MJ, Onwuteaka-Philipsen BD, Achterberg WP, Ribbe MW, Deliëns L, de Vet HC. Improved end-of-life care for patients with dementia: greater family satisfaction and possibly greater end-of-life comfort. *Ned Tijdschr Geneesk* 2013;157(17):A5324.
26. van der Steen JT, Ribbe MW, Deliëns L, Gutschow G, Onwuteaka-Philipsen BD. Retrospective and prospective data collection compared in the Dutch End Of Life in Dementia (DEOLD) study. *Alzheimer Dis Assoc Disord* 2014 Jan-Mar;28(1):88-94.
27. Hendriks SA, Smalbrugge M, Hertogh CM, van der Steen JT. Dying with dementia: symptoms, treatment, and quality of life in the last week of life. *J Pain Symptom Manage* 2014 Apr;47(4):710-20.

Chapter 6

When do patients with dementia receive spiritual care at the end of life?

Predictors of spiritual care provision for patients with dementia at the end of life as perceived by physicians: a prospective study

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ABSTRACT

Background

Spiritual caregiving is part of palliative care and may contribute to wellbeing at the end of life. However, it is a neglected area in the care and treatment of patients with dementia. We aimed to examine predictors of the provision of spiritual end-of-life care in dementia as perceived by physicians coordinating the care.

Methods

We used data of the Dutch End of Life in Dementia study (DEOLD; 2007–2011), in which data were collected prospectively in 28 Dutch long-term care facilities. We enrolled newly admitted residents with dementia who died during the course of data collection, their families, and physicians. The outcome of Generalized Estimating Equations (GEE) regression analyses was whether spiritual care was provided shortly before death as perceived by the on-staff elderly care physician who was responsible for end-of-life care (last sacraments or rites or other spiritual care provided by a spiritual counselor or staff). Potential predictors were indicators of high-quality, person-centered, and palliative care, demographics, and some other factors supported by the literature. Resident-level potential predictors such as satisfaction with the physician's communication were measured 8 weeks after admission (baseline, by families and physicians), physician-level factors such as the physician's religious background midway through the study, and facility-level factors such as a palliative care unit applied throughout data collection.

Results

According to the physicians, spiritual end-of-life care was provided shortly before death to 20.8% (43/207) of the residents. Independent predictors of spiritual end-of-life care were: families' satisfaction with physicians' communication at baseline (OR 1.6, CI 1.0; 2.5 per point on 0–3 scale), and faith or spirituality very important to resident whether (OR 1.9, CI 1.1; 3.3) or not (OR 1.5, CI 1.1; 2.0) of importance to the physician. Further, female family caregiving was an independent predictor (OR 2.7, CI 1.1; 6.6).

Conclusions

Palliative care indicators were not predictive of spiritual end-of-life care; palliative care in dementia may need better defining and implementation in practice. Physician-family communication upon admission may be important to optimize spiritual caregiving at the end of life.

BACKGROUND

Spiritual caregiving may contribute to wellbeing at the end of life, as shown in palliative populations of mostly cancer patients.^{1–4} Spiritual caregiving in dementia may be a neglected area, with little research available.^{5–7} For example, in a UK hospital, religious beliefs of dementia patients were less frequently documented than in patients without dementia.⁸ Similarly, in a US nursing home setting, cognitively impaired residents less frequently received support or care by facility staff for spiritual needs.⁹

In dementia and at the end of life, spiritual caregiving poses particular challenges. For example, it may be difficult to predict the end of life, and to communicate verbally due to cognitive impairment, perhaps with superimposed acute illness.⁵ Conceptually, cognitive appraisal is part of some definitions of spirituality at the end of life.^{10,11} However, rituals and music may be recognized even in severe dementia.^{7,12–14} Further, recent reviews indicate that there is some evidence of beneficial effects, also in dementia, of spiritual interventions and spirituality and religiousness on, for example, coping, wellbeing, and behavior.^{6,7}

We do not know when patients with dementia do or do not receive spiritual end-of-life care. In long-term care settings, the provision of spiritual care has been associated with families' perception of better overall care in the last month of life.⁹ This retrospective work suggests that families appreciate spiritual end-of-life care, or, that a high quality of care standard promotes spiritual caregiving at the end of life. In addition to high-quality care, the related and overlapping notions of person-centered and palliative care may promote spiritual caregiving. That is, spiritual care is part of palliative care.¹⁵ Further, at the individual level spiritual care should be consistent with, so may be related to patient- and family-centered principles.^{5,16} It should therefore consider the individual spiritual background, and respect any sensitivities. An individualized approach is particularly important in western, secularized countries where physicians are often less spiritual or religious than their older patients.

However, prospective studies with a clear temporal relationship relating such variables to provision of spiritual end-of-life care later are lacking. To our best knowledge, no study has systematically reviewed potential predictors of the provision of spiritual end-of-life care. Further, spirituality is an important theme in the nursing literature, but less is known about physicians' perceptions of spiritual caregiving, even though they are part of the team or have an important role in the provision of palliative care at the end of life, which includes spiritual caregiving. To explore how to support the physician's role in the spiritual caregiving at the end of life, we examine potential predictors of the provision of spiritual end-of-life care as perceived by physicians in a cohort of newly admitted residents with dementia in the long-term care setting of the secularized country of the Netherlands.

METHODS

Design

Data were obtained from the Dutch End of Life in Dementia (DEOLD) study which involved both prospective data collection in 28 long-term care facilities and retrospective (after death only) data collection in 6 facilities with survival assessed up to summer 2011. The study's design is detailed elsewhere,¹⁷ and potential predictors for the secondary anal-

yses to address our research question are described in detail in Table 1. We used the data collected prospectively regarding a cohort of newly admitted residents; the assessments were performed between January 2007 and July 2010. The study protocol was approved by the Medical Ethics Review Committee of the VU University Medical Center. Families of residents enrolled in the study provided written informed consent to participate in the study shortly after the resident's admission.¹⁷

The main purpose of the DEOLD study was to assess factors associated with after-death patient outcomes. Inclusion criteria were newly admitted to a "psychogeriatric" ward/unit (almost all dementia) of a nursing home, or a residential home facility covered by elderly care physician services, a physician's diagnosis of dementia, admitted for long-term care, and having a family representative able to understand and write Dutch or English.

Physician and family caregiver assessments were conducted eight weeks after admission to the facility (baseline), semi-annually, and after death (around two months after death for family, and within two weeks for physicians; see also "Time frame" in Table 1). Physicians sometimes delegated assessment of dementia severity to nurses. The participating physicians also completed a questionnaire about personal, non-patient related characteristics midway through the study. We used the data of the physician who provided end-of-life care. The local coordinating physician of each of 17 physician teams of 17 long-term care organizations that covered the 28 facilities completed a questionnaire on facility characteristics at the start, midway through, and at the conclusion of the study.

Setting

Physicians were on the staff of the nursing home facilities and most were certified as elderly care physicians after a three-year vocational training.³⁹ Spiritual counselors were available and employed through the 17 long-term care organizations. Dutch long-term care facilities are required to offer spiritual care, and Bachelor or Master-level trained and certified spiritual counselors are available serving all denominations.⁴⁰ Formal spiritual care such as rituals by clergy from the community or visits by spiritual counselors on the staff was coordinated by physicians or arranged by families.

Outcome measure

The outcome was spiritual care provision "shortly before death" as perceived by the on-staff elderly care physician. For this, we combined the response options provided to the physician of "spiritual care provided involving the last sacraments, or another last rite," "no last rites but spiritual care was provided to patient by a spiritual counselor," and "no last rites but spiritual care was provided to the patient by nursing home staff not specialized in spiritual care." Referring to last rites, we also asked how many days before death these were administered.

Potential predictors

For hypotheses driven rather than data driven analyses, we searched for potential predictors in previous work and in the comprehensive DEOLD dataset in an iterative way and found that most referred to one or more of three concepts: (1) a higher quality of care overall, and more specifically, (2) a more individualized or more person-centered approach, including considering religious backgrounds, and (3) a palliative care approach, and further, (4)

possibly also to factors such as demographics. These concepts are related and overlap; for example, palliative care is person-centered by definition as it addresses the specific needs of individual patients and families¹⁵ but person-centered care is not necessarily palliative care. Table 1 lists the potential predictors at the level of facilities, physicians, and residents and their families along with variable definitions of items including timing and responses, and how they may be indicators of the three concepts above. Further, some potential predictors can indicate more concepts, for example, facilities with a strong religious affiliation may apply palliative care principles more consistently, and the affiliation has also been associated with more spiritual caregiving at the end of life in nursing homes³⁰ and more comfort in patients dying with dementia in long-term care facilities.³¹ However, it may also attract a specific group of patients which may result in increased chances of spiritual wishes being met.⁹ Further, urban areas may be more secularized, less familiar with last rites¹⁴ and also provide lower quality of care (Table 1). Finally, religious background related to an individualized approach rather than demographics because we referred to concordance of religious backgrounds as an indicator of an individualized approach if unrelated to the provision of spiritual end-of-life care. We classified these indicators that may relate to more concepts with the concept for which we felt the association was most likely, and preferably with the more specific concept (e.g., palliative care over quality of care). We anticipated that some factors would be associated with outcome in univariable analyses only, such as demographics as perhaps related to the stronger predictor of religious background.

We examined potential predictors of spiritual end-of-life care at the level of the resident and family—using the family caregiver's and physician's baseline assessment, at the physician level, and the facility level. At the latter level, for variables assessed multiple times such as enough nurse staffing, we selected the last assessment rather than the first, because the facility characteristics proximate to the time when most residents died are most likely to affect the outcome (i.e. the opposite direction, the patient-level outcome affecting facility characteristics is unlikely). With regard to communication variables with both a physician and a family perspectives, we opted for the family perspective for reasons of relevance and to avoid using the same perspective for predictor and outcome (assessed by the physician). As regards the quality of communication or the relationship with either the physician or the nurses, we selected the variables referring to the physicians as the focus of our work.

Selection of residents

We included 372 newly admitted residents, and 218 residents died (59%) during the assessment period. A complete physician's after-death assessment was available for 213 residents.¹⁷ We excluded 6 residents with missing outcome, resulting in 207 cases for analyses. The 88 physicians completed after-death assessments for 1 to 9 residents.

Analyses

We performed Generalized Estimating Equations (GEE) regression analyses to adjust for clustering with physicians and facilities (resident- and physician-level variables, and multivariable analyses) or facilities only. Associations of independent variables as defined in Table 1 were determined with the provision of spiritual end-of-life care as the dependent variable. We calculated confidence intervals (95% CI). From each of the three concepts (1–3), out of the four to six factors each operationalized with one or more variables in Table 1, based on the Wald chi-square, we selected for (theory-driven) multivariable analyses the

variable with the strongest association with the outcome in univariable analyses. From the category of other factors (4), we included all factors that were significant in univariable analyses. We also tested a (statistics-driven) model that included all variables that were significant in univariable analyses, regardless of the concept it may refer to. All analyses were performed with SPSS 20.0.0 (IBM, 2011).

Missing data and death before the baseline assessment

Some missing data were due to residents moving to other, non-participating facilities (6/7 who moved), in which case we invited the attending physician of the new facility to complete the resident-level assessments and the physician assessment. We then assessed only publicly available facility characteristics (e.g., number of beds). Missing physician-level items were mostly due to physicians changing employment status early. Other possibly non-at random missing data were mainly due to residents dying before the baseline assessment, before physicians and families had had a chance to complete it prospectively. For these residents we used shortened baseline assessments to retrospectively collect only the data deemed not particularly vulnerable to recall bias.

In 37 cases either the physician assessment (10; 8 with regular family caregiver assessments, 2 lacking the family caregiver baseline assessment) or the family caregiver assessment (4; with regular physician assessments) or both (22) were only performed after death, and in one case the physician completed the baseline questionnaire almost nine months later yet still before death. We examined whether the outcome and potential predictor variables differed between the 24 (2 + 22) cases completely lacking prospective data and the other 183 cases.

Missing data were imputed with the multiple imputation procedure implemented in SPSS. For multiple imputation in multivariable analyses, we used the information of all full, single, variables with significant associations in univariable analyses; for variables related to religion, faith or spirituality, we selected the strongest of either resident or family to avoid collinearity and redundancy. We customized for 15 imputed datasets, and a maximum of 50 iterations, and the “predictive mean matching” option to avoid out-of-range imputations. We calculated ORs and 95% CIs from the summary coefficients and SE. For comparison, we also ran the multivariable model with simple imputation of mode and mean scores. To check for possible differences due to selective missing, we repeated the procedure limiting to the 183 cases for which prospectively collected data were available, and also examined addition of, and interaction with, a variable that adjusted for this in analyses of the full dataset.

RESULTS

Table 2 and the left columns of Tables 3, 4, 5 and 6 describe the facilities, physicians, residents and their families grouped by the concept they may refer to. The facility size was variable (11–210 beds) and a minority were residential homes, had a religious affiliation or were urban (Table 2). Less than half (10/28) had small-scale living arrangements or a palliative care unit, and the coordinating physician considered nurse staffing insufficient for half of facilities. Facility characteristics weighted for number of residents (Tables 3, 4, 5 and 6) were largely similar, except for small-scale living arrangements, which in some facilities were available for only some of the residents.

The residents and family caregivers were mostly female; mean ages were 85.3 and 61.1 years respectively (Table 6). Most physicians had a specific religious background (61.3%; Table 4), yet less than one-third of them considered faith or spirituality very important (31.2%), and most (53.2%) never attended religious services. The residents also frequently had a specific religious background (76.9%; Table 4), but in pairwise comparisons, in a quarter of cases (25.7%) only the resident had any such background where the physician had only in 12.6% of cases. Similar to the physicians, less than one-third of the residents (31.3%) found faith or spirituality very important, but the majority (62%) had attended religious services. Fewer families reported faith or spirituality being very important (21.6%), and on religious background (63.9%) or never attending services (50.3%) they were closer to the physicians than to the residents (Table 4). In 80.4% of cases, the resident having or not having a religious background corresponded with the family (not in Table).

Table 1 Potential predictors of the provision of spiritual end-of-life care through previous work, and definitions

Potential predictor (4 categories of which 3 indicate specific concepts)	Justification of possible predictive properties and expected association through previous work	Operationalization	
		Variable and measurement level*	Definitions of variable and response options, missing data
(1) Quality of care			
Long-term care facility type / physician presence	Dutch and US physicians who are more present are more certain of family preferences. ¹⁸ Further, better quality of end-of-life care was reported in Dutch nursing homes compared to residential homes. ¹⁹	Nursing vs. residential home	Definition: Dutch nursing homes have elderly care physicians on the staff, and outreach to units for dementia in residential homes of the same organization with no continuous physician presence.
		Facility	Time frame: Unchanged throughout data collection; for residents who moved: refers to location after move. Perspective: Coordinating physician and if missing, assessed through the facility's website. Missing data: No missing values.
Urbanization level	Better overall quality of care was provided in less urbanized areas according to some reports on nursing home care in the Netherlands (references in Dutch provided elsewhere). ¹⁹ It should be noted that secularization may be prominent in urbanized areas, which suggests it might also relate to spiritual caregiving in other ways.	Located in town vs. large city	Definition: Facility located in small city, town, village, or rural area versus in one of the four largest cities, all in the western part of the Netherlands. Time frame: Unchanged throughout data collection; for residents who moved: refers to location after move. Missing data: No missing values.
		Facility	
Staffing	Quality of care was lower with nursing staff shortage and higher turnover. ²⁰⁻²³	Enough nursing staff	Definition: Sufficiency of nursing staff as perceived by the coordinating physician Time frame: Conclusion of data collection. Perspective: The coordinating physician. Response options: More than enough, just enough (combined), versus not enough. Missing data: Loss to follow up- for those who moved to another facility (6 cases) was coded as missing.
		Facility	
Evaluation of quality of care – overall	An association of spiritual caregiving with family satisfaction with end-of-life care has been reported in a US study. ⁹	Satisfaction with care	Definition: Perception or satisfaction of care measured with the End-of-Life in Dementia-Satisfaction With Care (EOLD-SWC) scale. ²⁴ It represents quality of care as perceived by families. ²⁵ Time frame: We used the baseline assessment† which referred to the first 8 weeks after admission. The EOLD-SWC has been used for timeframes other than the last period before death in other prospective work as well. ²⁶ Perspective: Family. Response options: 10 4-point items are summed and total scores range 10–40, with higher scores representing better quality of care. Missing data: Missing values (40) include non-random missing for those who died before the baseline assessment.
		Resident	

Evaluation of quality of care – communication specifically

Communication with families may be specifically important for the physician to optimally coordinate care, including spiritual care. Further, communication is a major aspect of quality of end-of-life care and families' evaluation – i.e., satisfaction with end-of-life care including "timeliness of information, counseling" and "inter-personal and communication style" is an important outcome on its own.²⁷

(2) A more individualized or more person-centered approach of care; religious backgrounds

Philosophy of care related to individualized approach

Individualized person-centered approach: home-like, small-scale living might involve a more individualized approach. The literature on studies performed in the Netherlands reports it possibly relates to better quality of life although unclear how it relates exactly to quality of care.^{28,29}

Religious affiliation

In a US study, religiously-affiliated facilities were comparable to nonaffiliated facilities in providing on-site religious services, but more likely to provide individual counseling by clergy or chaplains.⁹ Therefore, a more individualized approach to spiritual caregiving may be assumed. US nursing homes with a religious affiliation were more likely to provide spiritual end-of-life care to their residents.³⁰ Further, nursing homes with a strong religious affiliation also provided better end-of-life care in a previous Dutch study,³¹ and more religion-oriented homes might also adhere to a palliative care approach more strongly.

Religious backgrounds and concordance care provider - patient

Families and physicians with any specific background may be more attentive to an individual's spiritual needs. An individualized person-centered approach is indicated by spiritual care more frequently being provided to residents with a specific religious background in particular when the physician does not have a specific background. That is, providing spiritual care when physician and patient have the same spiritual background does not need a special individualised approach, but it is indicative of such approach if spiritual care is being provided despite dissimilar spiritual backgrounds.

Satisfaction with communication

Resident

Definition: Item: "Are you satisfied with how the communication with the physician(s) is going (discussions on future care, goals of treatment, and current care)?"

Time frame: Baseline.[†]

Perspective: Family.

Response options: We created a 0–3 satisfaction scale with the response options: "satisfied in every respect" (3), "satisfied about the main elements (2)," "neutral" (1), "not satisfied" (0), "did not talk to physician(s) yet, while I would have wanted to (0), did not talk to physician(s) yet and I do not think that is needed yet (1).

Missing data: Missing values (37) include non-random missing for those who died before the baseline assessment.

Small-scale living Facility / resident

Definition: Small-scale living arrangement for dementia available. **Response options:** At the facility level (descriptive; patient-level data used for analyses): all of the residents the facility enrolled in the study; some of the residents; no small-scale living for dementia available.

Time frame: Assessed at the conclusion of the study for the period of data collection, and any changes during that period.

Missing data: 1 case.

Definition: Strong, explicit religious affiliation in place versus no affiliation or only historically.

Timeframe: Unchanged throughout data collection; for residents who moved: refers to location after move.

Perspective: Assessed by coordinating physician in discussions with researcher.

Missing data: No missing values.

Strong religious affiliation

Facility

Religious background Physician, resident

Definition: Any specific religious background.

Response options: We combined any specific religious background ("Protestant," "Catholic," "Muslim," "Humanist," "Jewish," and "other") versus "no specific religious background" for physicians (self-report), and families and residents (family report). We also created a variable that compared such background of the physician and the resident.

Time frame: Residents and families: baseline assessment.[†] For families, we used the religion of the family who completed the baseline assessment. Physician's religious background was assessed midway study.

Missing data: 21 physician responses, 12 for residents, and 13 for families. Resident-physician combined: 32 missing values.

Importance of faith or spirituality in life and concordance care provider – patient	An individualized person-centered approach is indicated by spiritual care more frequently being provided to residents for whom faith or spirituality was important in life, as found in a US study, ³⁰ and in particular when the physician does not find it important for him- or herself.
Religious activities involvement	An individualized person-centered approach is indicated by spiritual care more frequently being provided to residents who used to attend religious services more frequently. It parallels the outcome which also refers to formal and visible spiritual care provision, including explicit reference to rituals.
Quality of family-physician relationship	Assuming that trust is built up when relationships develop favorably, it may indicate a more individualized approach.
(3) Palliative care	
Palliative care explicitly provided at location	A positive spill-over effect of US hospice services on hospitalization rates of nursing home residents who were not on hospice has been noted by

Importance of faith or spirituality	Definition: Item: "How important is (resident: was) faith or spirituality in your life (resident: to your family/loved one)?" Response options: We tested "very important" versus "somewhat important," "not at all important," and "don't know" because there was not always a stepwise increase for the three hierarchical levels, and the distributions did not always allow for analyzing the full categorical variables with a reference category. We also created a variable that compared the physician's and the resident's faith or spirituality being very important. Time frame: Same as religious background. Perspective: Physicians (self-report), families and residents (family report). Missing data: Same as religious background.
Physician, resident	
Frequency of attending religious services	Definition: Item: "How often do you attend church or other religious services?" Response options: "More than once a week," "every week," "two or three times a month," "once a month or so," "once or twice a year," "never," and, for families only, regarding residents and themselves, "don't know." We transformed the responses into a 0–5 scale, recoding don't know as missing and after confirming there was a stepwise increase in the association with the outcome. Time frame: Same as religious background. Perspective: Physicians (self-report), families and residents (family report). Missing data: 21 physician responses, 13 for residents, and 14 for families.
Physician, resident	
Family trust	Definition: Item: "How much trust do you put in that the physician involved in care for your family/loved one tries hard to make the best of it for your family/loved one?" Response options: We created a 1–5 scale with the response options "a very large amount of trust (5)," "a great deal (large amount) of trust (4)," "somewhat trust (3)," "little trust (2)," and "very little trust (1)." Time frame: Baseline assessment. [†] Perspective: Families. Missing data: Missing values (37) included non-random missing for those who died before the baseline assessment.
Resident	
Palliative care unit	Definition: Palliative care unit (not commonly used for dementia patients) available in the facility vs. not available. Time frame: At start of data collection, and confirmed unchanged midway and at conclusion of data collection. Perspective: Coordinating physician.
Facility	

Palliation as the care goal that takes priority	Different care goals may coexist, but palliative care may be compatible with prioritizing comfort and maintaining function. ⁵	Comfort goal of care Resident	Definition: The care goal that takes priority. A comfort goal combines "palliative" and "symptomatic" with explanation that both are aimed at wellbeing and quality of life with only for a symptomatic additional prolonging of life being undesirable, ³³ versus "life prolongation," "maintaining or improving of functioning," "other," or "no global care goal assessed yet." We did not include functioning for a better distribution.
Anticipating death	Palliative care explicitly refers to dying as a normal process, and the prevention of suffering by means of early identification. ¹⁵ Further, quality of end-of-life care may be better when death is expected, with more opportunities to arrange the care the resident needs, and ensure a comfortable death. ³⁶	Death expected Resident Perception of dementia as a disease you can die from Resident	Time frame: Baseline, [†] after the care planning meeting which Dutch law requires within 6 weeks from admission. ^{34,35} Perspective: Physician. Missing data: Missing values (37) included non-random missing for those who died before the baseline assessment. Definition: Item: "If you think back to one month before your family/loved one died, do you feel like at that time you expected that he/she was going to die?" Time frame: After-death assessment. [†] Perspective: Family. Response options: "Yes," "no," "don't know." For analyses, we combined the last two options. Missing data: Missing values (31) included non-random missing values for those who died before the baseline assessment.
Recognizing terminality (4) Other factors or unclear expectation with regard to the direction of a possible association	Recognizing dementia as a terminal disease may be a basis for the provision of palliative care. In the DEOLD study, when families believed dementia was a disease you can die from, the resident had a more comfortable death. ³⁴ It may therefore also indicate better quality of care.	Perception of dementia as a disease you can die from Resident	Definition: Item: "In your opinion, dementia is a disease you can die from." Time frame: Baseline assessment [†] Perspective: Family. Response options: "Completely disagree," "partly disagree," "neither agree, nor disagree," "partly agree," "completely agree" and "do not know." We used a 1–5 agreement scale combining "don't know" and "neither agree, nor disagree." ³⁴ Missing data: Missing values (38) included non-random missing values for those who died before the baseline assessment.
Facility size and type	The literature reports associations with quality of care in opposite directions; references are provided elsewhere (online Annex). ¹⁷	Number of beds	Definition: Number of psychogeriatric (dementia) care beds in the facility. Timeframe: If changed during data collection, we calculated the mean number of beds over assessments at the start, mid-way and conclusion of the data collection period. Missing data: No.
Demo-graphics	Residents of small US residential homes / assisted living facilities (< 16 beds) were less likely to receive spiritual end-of-life care. ³⁰ A US study found no significant association with resident gender or age in unadjusted (univariable) analyses [9]. However, demographics may relate to religiousness.	Facility Gender and age Physician, resident	Definition and perspective: Gender and age of physician (physician report) and of family and resident (family report). We report on the physician involved in end-of-life care, and the family involved at baseline. Timeframe: All refer to the age when the resident died. Missing data: 12 for physicians, 0 for residents, and for families, 2 missing gender and 12 missing age.

Dementia severity	Less severe dementia may be associated with more frequent spiritual care in parallel with less frequent care compared to patients without dementia. ^{8,9}
Closeness of relationship	Individualized approach yet not attributable to professional caregivers. Spouses and children may be more cognizant regarding the resident's spiritual needs and background compared with other informal caregivers.

*Family and resident level are the same, because families provided a single after-death assessment on their deceased relative.

† Time frame: "baseline" refers to a resident-level assessment eight weeks after admission to the facility, "after death" was around two months after death for family, and within two weeks after death for physicians

Dementia severity	Definition: Bedford Alzheimer Nursing Severity-Scale (BANS-S) score, range 7–28 [37]. Scores of 17 and higher represent severe dementia [38].
Resident	Timeframe: Baseline. [†] Perspective: Physician (this item was completed by the nurse supervised by the physician in 68.9% of cases).
Relationship	Missing data: 4 missing values. Definition and response options: Relationship with resident of family involved at baseline: "spouse" combined with "partner;" "child;" and "other" which combined "grandchild," "sibling," "niece/nephew," "legal guardian, and "other."
Resident	Timeframe: Baseline. [†] Perspective: Family. Missing data: 12 missing values.

Table 2. Characteristics of facilities in which the selected residents resided including after having moved to other facilities

Numbers refer to number of facilities unless indicated otherwise	Facility of	
	Admission (n = 28)	Death (n = 34)
Nursing home	23	29
Residential home	5	5
Strong religious affiliation	3	3
No religious affiliation or only historically	25	31
Located in town	23	27
Located in large city	5	7
Staffing: enough nursing staff	14	-*
Staffing: not enough	14	
Palliative care unit	10	-*
No palliative care unit	18	
Small-scale living for dementia: all residents	5	-*
Small-scale living for dementia: some of the residents	5	
No small-scale living for dementia available	18	
Facility size – number of psychogeriatric (dementia) care beds, range	11-210	11-210

*Data not available from the 6 non-participating facilities to which 6 of 7 residents moved.

Table 3. Univariable associations of the provision of spiritual end-of-life care as perceived by physicians with potential predictors related to quality of care

	Descriptives	Spiritual care at the end of life [‡]		Association with the provision of spiritual care; OR (95% CI) Significant associations are italicized and bolded
		Provided	Not Provided	
Facility level*				
Nursing home vs. residential home, %	92.3	83.7	94.5	0.32 (0.08; 1.2)
Located in town versus large city, %	19.8	14.0	21.3	0.33 (0.09; 1.2)
Enough nursing staff, %	50.0	52.4	49.4	1.4 (0.48; 4.0)
Resident level				
Satisfaction with care (mean EOLD-SWC score, SD)	30.3 (4.2)	31.7 (3.9)	29.9 (4.2)	1.10 (1.01; 1.21)
Satisfied with communication with the physician				
– mean 0–3 scale (SD) [†]	1.7 (1.0)	2.1 (0.88)	1.6 (1.1)	1.6 (1.1; 2.3)
– percentage				per point increment
-not satisfied	7.1	2.9	8.1	
-no talk but had wanted to	10.6	5.9	11.8	
-neutral	18.8	5.9	22.1	
-no talk but accepted	1.8	0	2.2	
-satisfied about the main elements	36.5	50.0	33.1	
-satisfied in every respect	25.3	35.3	22.8	

EOLD-SWC = End-Of-Life care in Dementia–Satisfaction With Care; range 10–40 with higher scores representing more satisfaction.

*Facility characteristics refer to the facility where resident died (34 facilities; in 200 cases, same as facility of admission; in 7 cases, other facility) and descriptives are weighted for number of residents who died in the facility.

[†]In 0–3 scale, combined “no talk but had wanted to” with “not satisfied” and “no talk but accepted” with “neutral.”

[‡]For dichotomous variables, the proportion for which spiritual care was provided and not provided can be calculated as well reconstructing the 2x2 table and taking into account possible missing values as listed in Table 1. For example, 0.923 * 207 (no missing values) = 191 resided in nursing homes, so 207 – 191 = 16 in residential homes. Of those for whom spiritual end-of-life care was provided (43), 0.837*43 = 36 resided in nursing homes, so 7 in residential homes. The proportions (percentages) who were provided spiritual care at the end of life, were therefore 36/191 (18.8%) life in nursing homes, and 7/16 (43.8%) in residential homes.

Table 4. Univariable associations of the provision of spiritual end-of-life care as perceived by physicians with potential predictors related to individualized, person-centered care and religiousness variables

	Descriptives	Spiritual care at the end of life [‡]		Association with the provision of spiritual care; OR (95% CI) Significant associations are italicized and bolded
		Provided	Not Provided	
Facility level*				
Small-scale living, % (at resident level)	18.0	14.3	18.9	0.78 (0.27; 2.3)
Strong religious affiliation,%	9.2	30.2	3.7	9.9 (1.6; 62)
Physician level				
Any specific religious background physician, %	61.3	74.4	57.8	1.9 (0.73; 5.0)
Importance of faith or spirituality physician, %				
– not at all important	13.4	10.3	14.3	2.7 (1.1; 7.0)
– somewhat important	48.4	38.5	51.0	(very important versus other)
– very important	31.2	48.7	26.5	
– don't know	7.0	2.6	8.2	
Frequency of attending religious services physician				
– mean 0–5 scale (SD)	1.2 (1.6)	2.2 (1.9)	0.9 (1.4)	1.6 (1.2; 2.1)
– percentage				(per 1-point increment)
–never	53.2	30.8	59.2	
–once or twice a year	14.5	15.4	14.3	
–once a month or so	11.3	12.8	10.9	
–two or three times a month	7.5	5.1	8.2	
–every week	8.6	20.5	5.4	
–more than once a week	4.8	15.4	2.0	
Resident level				
Any specific religious background resident, %	76.9	97.4	72.0	13 (1.6; 103)
Any specific religious background, %				
– both resident and physician	49.1	74.3	42.9	17 (2.1; 131)
– resident only	25.7	22.9	26.4	8.6 (0.92;80)
– physician only	12.6	0	15.7	Reference
– neither	12.6	2.9	15.0	Reference [‡]
Importance of faith or spirituality resident, %				
– not at all important	34.9	5.3	42.0	12 (5.1; 28)
– somewhat important	30.8	18.4	33.8	(very important versus other)

– very important	31.3	76.3	20.4	
– don't know	3.1	0	3.8	
Faith or spirituality very important, %				
– both resident and physician	14.3	40.0	7.9	21 (6.1; 74)[¶]
– resident only	16.0	37.1	10.7	15 (5.2; 44)[¶]
– physician only	17.1	8.6	19.3	2.0 (0.44; 9.1)
– neither	52.6	14.3	62.1	Reference
Frequency of attending religious services resident				
– mean 0–5 scale, SD	2.0 (2.0)	3.6 (1.6)	1.6 (1.8)	1.8 (1.4; 2.2) /
– percentage				1-point increment
–never	37.9	5.3	45.9	
–once or twice a year	14.4	15.8	14.0	
–once a month or so	2.6	0	3.2	
–two or three times a month	9.2	7.9	9.6	
–every week	23.1	34.2	20.4	
–more than once a week	12.3	36.8	6.4	
–don't know	0.5	0	0.6	
Any specific religious background family, %	63.9	89.5	57.7	5.5 (2.2; 14)
Importance of faith or spirituality family, %				
– not at all important	36.1	7.9	42.9	4.5 (2.1; 9.9)
– somewhat important	39.2	44.7	37.8	(very important versus other)
– very important	21.6	47.4	15.4	
– don't know	3.1	0	3.8	
Frequency of attending religious services family				
– mean 0–5 scale, SD	1.1 (1.6)	2.6 (1.9)	0.79 (1.2)	1.9 (1.5; 2.3) /
– percentage				1-point increment
–never	50.3	18.4	58.1	
–once or twice a year	24.4	23.7	24.5	
–once a month or so	5.7	7.9	5.2	
–two or three times a month	6.7	10.5	5.8	
–every week	6.7	13.2	5.2	
–more than once a week	6.2	26.3	1.3	
–don't know	0	0	0	
Family trust in physician				
– mean 1–5 scale (SD)	4.04 (0.61)	4.12 (0.54)	4.01 (0.62)	1.3 (0.67; 2.3) /
– percentage				1-point increment
–very little	0	0	0	
–little	0.6	0	0.7	
–somewhat	14.7	8.8	16.2	
–a great deal (large amount)	65.3	70.6	64.0	
–a very large amount	19.4	20.6	19.1	

*Facility characteristics refer to the facility where resident died (34 facilities; in 200 cases, same as facility of admission; in 7 cases, other facility) and descriptives are weighted for number of residents who died in the facility. Small-scale living represent resident-level analyses.

†The footnote to Table 3 provides an example of how to reverse column and row percentages of dichotomous variables to result in proportions of residents who were provided spiritual end-of-life care with each of two response options.

‡Estimates do not converge with the last category only as the reference; we therefore combined with the before-last category.

§p = 0.558 for difference between upper two options.

Table 5 Univariable associations of the provision of spiritual end-of-life care as perceived by physicians with potential predictors related to palliative care

	Descriptives	Spiritual care at the end of life [†]		Association with the provision of spiritual care; OR (95% CI) Significant associations are italicized and bolded
		Provided	Not Provided	
Facility level*				
Palliative care unit, %	38.5	38.1	38.6	0.72 (0.17; 3.1)
Resident level				
Comfort goal of care, %	62.4	60.6	62.8	0.77 (0.34; 1.7)
Family expected death one month before, %				
– yes	33.0	35.9	32.1	1.2 (0.67; 2.3)
– no	59.7	56.4	60.6	(expected versus other)
– don't know	7.4	7.7	7.3	
Perception of dementia as a disease you can die from	3.4 (1.2)	3.1 (1.2)	3.5 (1.2)	0.82 (0.57; 1.2) / per 1-point increment agreement
– mean 1–5 scale				
– percentage				
–completely disagree	9.5	14.7	8.1	
–partly disagree	8.3	8.8	8.1	
–neither agree, nor disagree	13.6	23.5	11.1	
–partly agree	14.2	11.8	14.8	
–completely agree	26.6	17.6	28.9	
–don't know	27.8	23.5	28.9	

*For facility level, descriptives are weighted for number of residents who died in the facility.

†The footnote to Table 3 provides an example of how to reverse column and row percentages of dichotomous variables to result in proportions of residents who were provided spiritual end-of-life care with each of two response options.

Table 6. Univariable associations of the provision of spiritual end-of-life care as perceived by physicians with potential predictors related to quality of care

	Descriptives	Spiritual care at the end of life [†]		Association with the provision of spiritual care; OR (95% CI) Significant associations are italicized and bolded
		Provided	Not Provided	
Facility level*				
Facility size, number of psychogeriatric (dementia) care beds	110 (SD 51)	96 (58)	113 (58)	0.991 (0.982; 1.000)* / bed
Physician level				
Female gender physician, %	62.6	65.9	61.7	1.1 (0.46; 2.8)
Age physician (resident level), mean number of years (SD)	43.1 (8.7)	42.1 (9.1)	43.4 (8.7)	1.00 (0.95; 1.05) per year
Resident level				
Female gender resident, %	66.2	67.4	65.9	1.2 (0.52; 2.6)
Age resident, mean (SD)	85.3 (6.4)	86.4 (5.9)	85.1 (6.5)	1.03 (0.97; 1.09) per year increment
Dementia severity, mean BANS-S score (SD)	14.6 (4.5)	15.3 (4.3)	14.4 (4.5)	1.03 (0.96; 1.11) per point increment
Female gender family, %	61.5	72.1	58.6	2.4 (1.1; 5.1)
Age family, mean (SD)	61.1 (11.7)	58.6 (10.2)	61.7 (12.0)	0.97 (0.94; 1.01) per year increment
Relationship family with resident, %				
– spouse or partner	20.0	15.4	21.2	Reference
– child	59.5	66.7	57.7	1.5 (0.59; 4.0)
–other	20.5	17.9	21.2	1.3 (0.43; 3.8)

*For facility level, descriptives are weighted for number of residents who died in the facility.

†The footnote to Table 3 provides an example of how to reverse column and row percentages of dichotomous variables to result in proportions of residents who were provided spiritual end-of-life care with each of two response options.

‡p = 0.046.

Regarding quality of care at baseline (Table 3), only one-quarter of families (25.0%) were satisfied with the communication with the physician in every respect. Over one in ten (12.4%) had not yet talked to the physician at 8 weeks from admission, and this was dissatisfying to most (18/21 of those who had not yet talked to the physician; overall 10.6%, and 1.8% who accepted it, Table 3). Regarding palliative care (Table 5), the physicians reported a comfort goal of care at baseline for most residents (62.4%). Only one-third of families (33.0%) reported having expected death the month before.

Spiritual end-of-life care

According to the physicians, spiritual end-of-life care was provided shortly before death to a total of 20.8% (43/207) of residents. This involved pastoral care with last sacraments, or another last rite (overall 8.2%; 40%, 17/43 of those for whom spiritual end-of-life care was provided), provided on average 2.5 days before death (SD 2.0, range 0–8 days). Further, a spiritual counselor provided other types of spiritual care for 11.1% of residents (53%, 23/43 of those for whom spiritual end-of-life care was provided) and a staff member not specialized in spiritual care did so in 1.4% of cases (7%, 3/43 of those for whom spiritual end-of-life care was provided). The 24 residents for whom prospective data was lacking completely were equally likely to receive spiritual end-of-life care (25.0% versus 20.2% in other 183 cases; $p = 0.56$).

Single potential predictors of spiritual end-of-life care

In univariable analyses, families' baseline satisfaction with care, and satisfaction with physician communication predicted the provision of spiritual end-of-life care (Table 3). Further, residents of facilities with a strong religious affiliation were more likely to receive spiritual end-of-life care as perceived by the physicians (Table 4). The physician's religious background was unrelated, but residents whose attending physicians found faith or spirituality very important in life, or who attended religious services more frequently, were more likely to receive such care. Similarly, the importance attached to faith or spirituality and attending services by resident and family predicted the provision of spiritual end-of-life care, but having any such background was also predictive.

The physician as well as the resident having a spiritual background (compared to physician only or neither) predicted receipt of spiritual end-of-life care (OR 17, CI 2.1;131), but the association was less strong and not significant if the resident had such a background and the physician did not (OR 8.6; CI 0.92;80). The main predictor of the importance of faith or spirituality item in relation to spiritual end-of-life care was the resident finding it important, irrespective of the physician attaching importance to it ($p = 0.56$ for "resident only" when reference reversed to upper category "both resident and physician"). Trust was not significantly associated with the outcome.

Further, none of the indicators of palliative care was significantly associated with the outcome (Table 5). Of the other factors, a smaller number of dementia care beds was predictive, in addition to family caregivers being female (Table 6), also when adjusted for the three variables indicating religion, spirituality or faith.

Of all items listed in Tables 3, 4, 5 and 6, only a few resident-level variables differed for the 24 residents who died soon after admission: on average, they were younger and had more severe dementia. The adjustment, however, did not change the ORs for age and dementia severity (remained 1.03 per year or point increment for both).

Independent predictors of spiritual end-of-life care

Independent predictors of the provision of spiritual end-of-life care when including the strongest predictor among the indicators of each of the concepts (the theory-driven model; Table 7) were resident-level factors: families' satisfaction with physician communication at baseline (OR 1.6, CI 1.0;2.5 per point on the 0–3 scale) and faith or spirituality very important to resident regardless of importance to the physician (OR 19, CI 5.6;63 and OR 15, CI, 5.1;47, respectively) versus not important for both. As in univariable analyses, none of the indicators for a palliative care approach was predictive. Further, residents with a female family caregiver at baseline were more likely to receive spiritual end-of-life care (OR 2.7, CI 1.1;6.6).

Table 7. Independent predictors of the provision of spiritual end-of-life care as perceived by physicians (n = 207, multivariable analyses with multiple imputation)

	Independent association with the provision of spiritual end-of-life care; OR (95% CI) Significant associations are italicized and bolded
(1)* Satisfied with communication with the physician, 0–3 scale	1.6 (1.04; 2.5) per point increment ($p = 0.034$)
(2) Faith or spirituality very important	
- both resident and physician	19 (5.6; 63)
- resident only	15 (5.1; 47)
- physician only	2.2 (0.46; 10)
- neither	Reference
(3) Family expected death one month before	
(4) (a) Facility size, number of psychogeriatric (dementia) care beds	1.3 (0.51; 3.3) 0.997 (0.987; 1.007) / bed
(b) Female gender family	2.7 (1.1; 6.6)

*The numbers between brackets refer to the categories as listed in Table 1 and univariable analyses presented in Tables 3, 4, 5 and 6: (1) Quality of care, (2) A more individualized or more person-centered approach of care; religious backgrounds, (3) Palliative care, (4) Other factors or unclear expectation with regard to the direction of a possible association.

When limiting to cases with prospective data (183/207), families' female gender was not a significant predictor, and the OR was somewhat smaller (2.1 vs. 2.7), also when compared to the full dataset with simple imputation (2.4, CI 1.2–4.8), but the results were similar when adjusted for missing prospective data and there was no significant interaction with gender. Analyses without imputation, and analyses including all the variables significant in the univariable analyses (the statistics-driven model) resulted in the same three variables being significantly associated with the outcome and no additional significant variables.

DISCUSSION

In our prospective study in Dutch long-term care, we found that independent predictors of the provision of spiritual end-of-life care in dementia as perceived by their physicians included families' reports of satisfaction with physicians' communication soon after admission (at baseline), and families' reports of faith or spirituality having been very important to the resident irrespective of the importance to the physician. These findings were robust to restriction of samples, imputation methods and theory-driven or statistics-driven regression methods. We also found that female caregiving was independently associated with spiritual end-of-life care but only when cases of death soon after admission were included.

Early established good family-physician communication may increase chances of spiritual caregiving. A retrospective study found that US residents of VA long-term care facilities were more likely to be visited by a chaplain if a family member was involved at the end of life.⁴¹ In our study, we also found that the caregiving was person-centered in the sense that physicians for whom faith or spirituality was unimportant for themselves also coordinated spiritual caregiving for the resident for whom this had been important.

Palliative care indicators as defined in our study were unrelated to spiritual end-of-life care, while spiritual care is explicitly included in definitions of palliative care.^{5,15} We may have lacked good indicators for palliative care, and such clear indicators may be needed and relevant beyond the particular study design. Dutch long-term care practice employs spiritual counselors, but the physicians may not have a clear view of what palliative care in dementia entails. There are no multidisciplinary specialist palliative care teams that explicitly support end-of-life caregiving as there are in Flanders,⁴² or the US (e.g., Li, et al.⁴³) where hospice was associated with more frequent provision of spiritual end-of-life care in a retrospective study in long-term care settings.³⁹ Moreover, a Dutch interview study showed that elderly care physicians employed variable definitions, and some emphasized withholding treatment rather than providing treatment for comfort.⁴⁴ Some also felt that all care for nursing home residents with dementia is palliative, rendering it an indiscriminative indicator for the setting. Further, few knew the definitions of care goals issued by the professional organization.³³ Moreover, unlike the WHO definition of palliative care and a recent definition of palliative care in dementia specifically,⁵ the palliative care goal definitions of the Dutch professional organization do not refer explicitly to spiritual caregiving, as they were developed to discriminate a palliative care goal from life-prolongation as a goal.³³

In our study about one in five (20.8%) residents received spiritual end-of-life care, which is much lower than in a US four-state study asking bereaved family on spiritual caregiving in the last month of life (72.4%).³⁹ It may be, however, an underestimation for the Netherlands, because the percentage was higher (47%, and mostly (38%) rituals) in the two organizations that we excluded from the analyses because they collected the data only retrospectively. These were situated in regions with a dominant Roman Catholic tradition. The predictors of spiritual end-of-life care, however, are not necessarily different in those areas.

Our outcome purposefully referred to spiritual care as perceived by the physician, suggesting more formal, religion-related and "visible" care in addition to any spiritual care provided by specialized and non-specialized staff. The last was provided in only 1.4% of cases. Nurses provide spiritual end-of-life care that is not formalized in care plans and is perhaps not documented either, as observed in Dutch ethnographic work.⁴⁵ Such spiritual caregiving may not have been noted by the physicians, but is covered in models of spiri-

tuality in the literature.^{11,46} Predictors for such an informal spirituality-focused rather than religiousness-focused outcome may be dissimilar; for example, such care may be brought about and affected by other factors than physician communication and importance of faith or spirituality.

Our work may be relevant for other countries. For example, physician presence may be important for communication as both US and Dutch physician's presence related to knowing family wishes better.¹⁸ Further, it may be relevant to systems where not the physician, but another professional may have the role of coordinating the care which may include spiritual care.

Limitations of our study include the operationalization of spiritual caregiving and the three related concepts we examined. For example, we could not cover the full concept of person-centered care⁴⁷ and we had the fewest variables for palliative care, one of which (death expected) was assessed only after death. Some of these variables were not indicative in themselves, but their association with outcome was, such as the combined importance attached to faith or spirituality by both physician and resident. The rationale for this variable indicating person-centeredness is that spiritual care should not be provided to those who previously found this unimportant. This may be called in question and some may argue that spiritual care, which is not necessarily religious, should be provided to all, and especially at the end of life and with dementia, unless there is clear evidence of reluctance on the part of the patient.

To the best of our knowledge, this is the first study prospectively relating status shortly after admission to spiritual end-of-life care, and the first to focus on spiritual end-of-life care for residents of long-term care facilities as perceived by physicians. The retrospective US four-state study on correlates of spiritual care did not include physician perceptions but family perceptions, and while they also found that the importance of spirituality/religion to the resident was a strong correlate,³⁹ there was no study of the importance to staff. A clear temporal relation reduces the risk of bias, but cautious interpretation as causal is still warranted because of the observational study design. Further, we did not follow all residents until death, so our sample selectively included more resident with a shorter length of stay, who were younger and had less advanced dementia, but there was no difference between the prospective and retrospective designs in important outcomes such as pain and comfort.¹⁷ With 28 facilities and 88 physicians in the analytic sample, the power for facility-level and physician-level variables to detect associations with outcome was smaller than for resident-level variables.

The first assessment in DEOLD was eight weeks after admission to long-term care, and future work may focus on establishing physician-family contact in the first weeks. Such work may be qualitative or quantitative observational or experimental and provide more detailed clues as to how to facilitate (spiritual) caregiving at the end of life. We did not relate spiritual caregiving to patient outcomes such as quality of life or comfort because these were also assessed after death. In cancer patients, others found that being visited by a pastor at the end of life as well as being treated as a whole person and with respect, and trusting and respecting their physician predicted quality of life at the end of life.⁴

CONCLUSIONS

Physician or staff-family communication as early as within weeks from admission to a long-term care facility may be important in the provision of (spiritual) end-of-life care. Palliative care, in the absence of organizational structures indicating this care is provided, may need better defining and implementation in clinical nursing home practice and should explicitly include additional aspects of care such as spiritual end-of-life care.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

JTS contributed to conception, design, acquisition of data, analysis and interpretation of data, and drafted the manuscript. M-JHEG, CMPM and LD contributed to analysis and interpretation of data, and revising the manuscript critically for important intellectual content. Sources of funding of the authors are the Universities to which they are affiliated, and the nursing homes to which M-JHEG and CMPM are employed. All authors read and approved the final manuscript.

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REFERENCES

- Vallurupalli M, Lauderdale K, Balboni MJ, Phelps AC, Block SD, Ng AK, Kachnic LA, Vanderweele TJ, Balboni TA: The role of spirituality and religious coping in the quality of life of patients with advanced cancer receiving palliative radiation therapy. *J Support Oncol* 2012, 10:81–87.
- Hills J, Paice JA, Cameron JR, Shott S: Spirituality and distress in palliative care consultation. *J Palliat Med* 2005, 8:782–788.
- Sinclair S, Chochinov HM: The role of chaplains within oncology interdisciplinary teams. *Curr Opin Support Palliat Care* 2012, 6:259–268.
- Zhang B, Nilsson ME, Prigerson HG: Factors important to patients' quality of life at the end of life. *Arch Intern Med* 2012, 172:1133–1142.
- van der Steen JT, Radbruch L, Hertogh CMPM, de Boer ME, Hughes JC, Larkin P, Francke AL, Jünger S, Gove D, Firth P, Koopmans RT, Volicer L, On behalf of the European Association for Palliative Care (EAPC): White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* 2014, 28:197–209.
- Bonelli RM, Koenig HG: Mental disorders, religion and spirituality 1990 to 2010: a systematic evidence-based review. *J Relig Health* 2013, 52:657–673.
- Ennis EM Jr, Kazer MW: The role of spiritual nursing interventions on improved outcomes in older adults with dementia. *Holist Nurs Pract* 2013, 27:106–113.
- Sampson EL, Gould V, Lee D, Blanchard MR: Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age Ageing* 2006, 35:187–189.
- Daaleman TP, Williams CS, Hamilton VL, Zimmerman S: Spiritual care at the end of life in long-term care. *Med Care* 2008, 46:85–91.
- Vachon M, Fillion L, Achille M: A conceptual analysis of spirituality at the end of life. *J Palliat Med* 2009, 12:53–59.
- Cobb M, Dowrick C, Lloyd-Williams M: Understanding spirituality: a synoptic view. *BMJ Support Palliat Care* 2012, 2:339–343.
- Buckwalter GL: Addressing the spiritual & religious needs of persons with profound memory loss. *Home Healthc Nurse* 2003, 21:20–24.
- Jewell A: *Spirituality and Personhood in Dementia*. London: Jessica Kingsley; 2011.
- Gijsberts MJ, van der Steen JT, Muller MT, Echteld MA, Hertogh CMPM, Deliens L: Spiritual end-of-life care in nursing homes: An exploratory study among physicians. In Congress program of the 15th *Congress of the International Psychogeriatric Association (IPA), the Hague*. ; 2011:93. Abstract. A full paper is under review.
- World Health Organization (WHO): *Definition of palliative care*. 2002. <http://www.who.int/cancer/palliative/definition/en/> Last accessed, February 7, 2014.
- Puchalski C, Ferrell B, Virani R, Otis-Green S, Baird P, Bull J, Chochinov H, Handzo G, Nelson-Becker H, Prince-Paul M, Pugliese K, Sulmasy D: Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *J Palliat Med* 2009, 12:885–904.
- van der Steen JT, Ribbe MW, Deliens L, Gutschow G, Onwuteaka-Philipsen BD: Retrospective and prospective data collection compared in the Dutch End of Life in Dementia (DEOLD) study. *Alzheimer Dis Assoc Disord* 2014, 28:88–94.
- Helton MR, Cohen LW, Zimmerman S, van der Steen JT: The importance of phy-

- sician presence in nursing homes for residents with dementia and pneumonia. *J Am Med Dir Assoc* 2011, 12:68–73.
19. van der Steen JT, van Soest-Poortvliet MC, Gijsberts M-JHE, Onwuteaka-Philipsen BD, Achterberg WP, Ribbe MW, Deliens L, de Vet HC: [Improved end-of-life care for patients with dementia: greater family satisfaction and possibly greater end-of-life comfort]. *Ned Tijdschr Geneeskde* 2013, 157:A5324.
 20. Bostick JE, Rantz MJ, Flesner MK, Riggs CJ: Systematic review of studies of staffing and quality in nursing homes. *J Am Med Dir Assoc* 2006, 7:366–376.
 21. Castle NG, Engberg J, Men A: Nursing home staff turnover: impact on nursing home compare quality measures. *Gerontologist* 2007, 47:650–661.
 22. Castle NG, Engberg J: Further examination of the influence of caregiver staffing levels on nursing home quality. *Gerontologist* 2008, 48:464–476.
 23. Lerner NB, Johantgen M, Trinkoff AM, Storr CL, Han K: Are nursing home survey deficiencies higher in facilities with greater staff turnover. *J Am Med Dir Assoc* 2014, 15:102–107.
 24. Volicer L, Hurley AC, Blasi ZV: Scales for evaluation of End-of-Life Care in Dementia. *Alzheimer Dis Assoc Disord* 2001, 15:194–200.
 25. van Soest-Poortvliet MC, van der Steen JT, Zimmerman S, Cohen LW, Munn J, Achterberg WP, Ribbe MW, de Vet HC: Measuring the quality of dying and quality of care when dying in long-term care settings: a qualitative content analysis of available instruments. *J Pain Symptom Manage* 2011, 42:852–863.
 26. Engel SE, Kiely DK, Mitchell SL: Satisfaction with end-of-life care for nursing home residents with advanced dementia. *J Am Geriatr Soc* 2006, 54:1567–1572.
 27. 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, 17:93–108.
 28. Verbeek H, Zwakhalen SM, van Rossum E, Ambergen T, Kempen GI, Hamers JP: Dementia care redesigned: Effects of small-scale living facilities on residents, their family caregivers, and staff. *J Am Med Dir Assoc* 2010, 11:662–670.
 29. de Rooij AH, Luijckx KG, Schaafsma J, Declercq AG, Emmerink PM, Schols JM: Quality of life of residents with dementia in traditional versus small-scale long-term care settings: a quasi-experimental study. *Int J Nurs Stud* 2012, 49:931–940.
 30. Hamilton VL, Daaleman TP, Williams CS, Zimmerman S: The Context of religious and spiritual care at the end of life in long-term care facilities. *Sociol Relig* 2009, 70(2):179–195. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3864041/>.
 31. Gijsberts MJ, van der Steen JT, Muller MT, Deliens L: [End-of-life with dementia in Dutch anthroposofic and traditional nursing homes]. *Tijdschr Gerontol Geriatr* 2008, 39:256–264.
 32. Miller SC, Gozalo P, Mor V: Hospice enrollment and hospitalization of dying nursing home patients. *Am J Med* 2001, 111:38–44.
 33. Hertogh C: Advance care planning and palliative care in the dementia: a view from the Netherlands. In *Supportive Care for the Person with Dementia*. Edited by Hughes C, Lloyd-Williams M, Sachs GA. New York: Oxford University Press Inc; 2009:271–280.
 34. van der Steen JT, Onwuteaka-Philipsen BD, Knol DL, Ribbe MW, Deliens L: Caregivers' understanding of the terminal nature of dementia predicts patients' comfort at death: a prospective observational study. *BMC Med* 2013, 11:105.
 35. Staatsblad: Besluit zorgplanbespreking AWBZ-zorg [Exceptional Medical Expenses Act, AWBZ]. 2012. <https://zoek.officielebekendmakingen.nl/stb-2009-131.html>] (Last accessed February 2015.).
 36. Munn JC, Hanson LC, Zimmerman S, Sloane PD, Mitchell CM: Is hospice associated with improved end-of-life care in nursing homes and assisted living facilities? *J Am Geriatr Soc* 2006, 54:490–495.
 37. Volicer L, Hurley AC, Lathi DC, Kowall NW: Measurement of severity in advanced Alzheimer's disease. *J Gerontol* 1994, 49:M223–M226.
 38. van der Steen JT, Volicer L, Gerritsen DL, Kruse RL, Ribbe MW, Mehr DR: Defining severe dementia with the Minimum Data Set. *Int J Geriatr Psychiatry* 2006, 21:1099–1106.
 39. Koopmans RT, Lavrijsen JC, Hoek F: Concrete steps toward academic medicine in long term care. *J Am Med Dir Assoc* 2013, 14:781–783.
 40. Netherlands Association of Spiritual Caregivers in Care Institutions (VGVZ) [Vereniging voor Geestelijk Verzorger in Zorginstellingen]: *Professional standard*. The Netherlands: VGVZ; 2005. (Last accessed February 2015)
 41. Sudore RL, Casarett D, Smith D, Richardson DM, Ersek M: Family involvement at the end-of-life and receipt of quality care. *J Pain Symptom Manage* 2014, 48:1108–1116.
 42. De Gendt C, Bilsen J, Stichele RV, Deliens L: Advance care planning and dying in nursing homes in Flanders, Belgium: a nationwide survey. *J Pain Symptom Manage* 2013, 45:223–234.
 43. Li Q, Zheng NT, Temkin-Greener H: Quality of end-of-life care of long-term nursing home residents with and without dementia. *J Am Geriatr Soc* 2013, 61:1066–1073.
 44. van Soest-Poortvliet MC: Barriers and facilitators of (timely) planning of palliative care in patients with dementia: a study in Dutch nursing homes. In *Part of Symposium "Palliative ways and means: Improving end of life care for people with dementia"*. The Hague: International Psychogeriatrics Association (IPA) 15th Congress; 2011. A full paper is under review.
 45. Gijsberts MJHE, van der Steen JT, Muller MT, Hertogh CM, Deliens L: Spiritual end-of-life care in Dutch nursing homes: an ethnographic study. *J Am Med Dir Assoc* 2013, 14:679–684.
 46. Gijsberts MJ, Echteld MA, van der Steen JT, Muller MT, Otten RH, Ribbe MW, Deliens L: Spirituality at the end of life: conceptualization of measurable aspects—a systematic review. *J Palliat Med* 2011, 14:852–863.
 47. Edvardsson D, Winblad B, Sandman PO: Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *Lancet Neurol* 2008, 7:362–367.

Chapter 7

Perceptions of spirituality and spiritual caregiving at the end of life in elderly care physicians a survey

Perceptions of spirituality and spiritual caregiving at the end of life in elderly care physicians practicing in long-term care. A nationwide survey in the Netherlands.

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SUBMITTED.

ABSTRACT

Background

In Dutch nursing homes, elderly care physicians are responsible for end-of-life care.

Objective

To examine how frequently Dutch elderly care physicians provide spiritual care at the end of life, if their perception of spirituality at the end of life corresponds with literature, and whether this perception relates to their provision of spiritual end-of-life care.

Methods

A cross-sectional survey with 642 physicians. It included questions about their last patient who died and the provided spiritual care. Physicians' perception of spirituality was measured with 15 items obtained from a systematic review of instruments that measure spirituality at the end of life. Fifteen additional non-spiritual items concerned psychosocial needs (10) and other issues (5)

Results

The response rate was 47.2%. 48.4% of the physicians reported they provided spiritual end-of-life care to the last resident they cared for. 51.8% of the physicians identified all 15 spiritual items. 95.4% included one or more psychosocial items in their perception of spirituality, 49.1% included at least one item on other issues. Physicians that included more non-spiritual items reported more often that they provided spiritual care, as did more religious physicians and those with additional training in palliative care.

Conclusions

Most physicians included non-spiritual issues in their perception of spiritual end-of-life care. With a broader perception of spirituality at the end-of-life, physicians reported more often that they provided spiritual end-of-life care. Also, more religiousness and additional training in palliative care was associated with reported provision of spiritual care by physicians. Further research is recommended on the concept of spirituality at the end of life. Additional training of elderly care physicians in reflecting their own perception of spirituality, distinguishing spiritual needs from psychosocial and other needs at the end of life, and training in multidisciplinary spiritual end of life care may contribute to quality of end-of-life care to nursing home residents.

INTRODUCTION

The spiritual dimension is the least developed dimension of palliative care.¹ The concept of spirituality is complex, which is a hindrance to spiritual caregiving at the end of life.² Patients often experience spiritual distress at the end of life, and various studies show that alleviation of spiritual distress contributes to spiritual and psychosocial wellbeing,^{3,4,5} and improves quality of life and quality of care.^{6,7}

In the US, UK and the Netherlands about a quarter of all older people die in nursing homes.^{8,9} An international study in over 21 countries showed that almost a fifth of all deaths of older people occur in nursing homes.¹⁰ Older nursing home residents have emphasized the importance of spirituality and spiritual care at the end of life,¹¹ and spiritual caregiving by nursing home staff is related to a better family evaluation of end-of-life care for nursing home residents.¹² Spiritual caregiving in dementia is considered especially difficult. An ethnographic study in a Dutch nursing home showed that spiritual issues in residents with and without dementia were only informally addressed by nursing staff.¹³ The European Association for Palliative Care published a white paper on palliative care in dementia and recommends assessment of religious affiliation, referral to an experienced spiritual counsellor and religious activities, such as rituals, songs and services.¹⁴

In the Netherlands on-staff elderly care physicians provide end-of-life care to residents in nursing homes.^{15,16} In most of the Dutch nursing homes the physician is also responsible for the contents of the resident's care plan, which should include all the needs of the resident.¹⁷ Most nursing homes have on-staff spiritual counsellors and psychologists. In a focus group study with Dutch elderly care physicians,¹⁸ the physicians underlined that it is important to distinguish spiritual needs from psychosocial needs. However, we have no representative data on how the physicians define spiritual issues as distinct from psychosocial issues and how often they feel they provide spiritual care.

In this study we examine how frequently Dutch elderly care physicians provide spiritual care at the end of life, to what extent their perception of spirituality at the end of life corresponds with items selected from validated instruments that measure spirituality at the end of life, and if the physicians' perception of spirituality relates to them providing spiritual end-of-life care.

METHOD

Design

We performed a cross-sectional survey among a representative sample of Dutch elderly care physicians who generally practice in long-term care, mostly nursing homes. A postal questionnaire was sent to half (642) of the 1248 elderly care physicians registered at Verenso (the Dutch Association of Elderly Care Physicians and Social Geriatricians), sampling alternately in alphabetical order of last names. The questionnaire was sent out in October 2012, and one reminder was sent to non-responders in November 2012. We received completed questionnaires until February 2013. The Medical Ethics Review Committee of the VU University Medical Center approved this survey as a part of a larger study protocol that comprised a series of studies on 'Spiritual care at the end of life in Dutch nursing homes.

The questionnaire

The provision of spiritual care at the end of life was measured with the item: “In your opinion, did you provide spiritual care to the last resident you cared for in the last month of life?”. We also asked: “Did you differentiate between psychosocial and spiritual needs in this resident?”

Based upon a literature review on instruments measuring spirituality at the end of life,¹⁹ we selected 15 items covering the various aspects of spirituality, such as spiritual wellbeing and spiritual activities.²⁰⁻²⁵ Fifteen additional, non-spiritual items were drawn from validated instruments measuring quality of life at the end of life.^{20,25} Ten of these non-spiritual items concerned psychosocial needs and 5 items addressed other issues (physical needs, medical/communicational, financial). The 30 items were presented in random order and introduced with: “In your opinion, spirituality at the end of life may comprise:” inviting respondents to include any number of items they perceived as being part of spirituality at the end of life.

Physician and practice characteristics were also part of the questionnaire. We measured religiosity with the Religious and Spiritual Beliefs and Practices Scale,²⁶ a self-administered tool with 5 questions previously used to measure religiousness of US general practitioners. Sum scores range from 5 to 21.

We pilot-tested an earlier version of the questionnaire among five elderly care physicians, asking specifically about user friendliness and clarity of the questionnaire. We improved the questionnaire based upon their responses and comments.

Analyses

We analysed non-response by comparing geographical distributions of respondents and non-respondents. We described the proportion of physicians who felt they provided spiritual care at the end of life, their differentiation between spiritual and non-spiritual items, and the physicians’ perceptions of spirituality at the end of life with proportions of the physicians that included the 30 items as belonging to spirituality at the end of life. We quantified the degree to which their perception of spirituality at the end of life corresponded with measurable and validated aspects of spirituality at the end of life in the literature in three ways. First, we counted the number of the 15 items that represented the literature on spirituality at the end of life they included. Second, we counted the number of non-spiritual items included that represented the non-spiritual aspects of quality of life at the end of life. Third, we calculated how close the physician’s perception was to the literature by subtracting the number of the 15 non-spiritual items the physicians included as belonging to spirituality from the number of the 15 spiritual items they included. Thus, a total score of +15 referred to complete consistency with the literature, and a total score of -15 referred to a complete opposite perception of spirituality, and a mean score of 0 was expected with random endorsing of items. We considered scores of +8 and higher (a minimum mean of +7.5, at least midway 0 and 15) to be reasonably consistent with the literature.

We imputed with item means if one of the 5 items of the Religious Beliefs and Practices Scale was missing, resulting in complete scores for all but two physicians. Very few data were missing overall, and we kept 5 cases with missing outcomes in the descriptive analyses only. Multivariable logistic regression was used to determine associations between the physicians’ perception of spirituality as the independent variable and the providing of

spiritual end-of-life care as the dependent variable, adjusted for physicians’ characteristics. We also adjusted for the total number of included items to avoid any influence of physicians possibly including (all) items unselectively. We tested interaction terms between the independent variable of interest and any physician characteristic significantly associated with the outcome. If needed in the multivariable regression, we imputed with mode or mean where appropriate. We calculated odds ratios (OR) and 95% confidence intervals. Data were analyzed using SPSS 20.0.0 (IBM Statistics, 2011).

RESULTS

The response rate was 47.2% (303/642 physicians), we found no selective response for different geographic regions (provinces). Of the respondents, 19 were no longer practising physicians and were excluded, resulting in an analytic sample of 284 cases.

Table 1 describes the physicians’ characteristics. The mean age was 46.7 years, and 66.0% were female. A small minority (10.7%) had had additional training in palliative care. Over half (56.9%) of the participants had no current denomination. The mean of the religiosity scale was 11.5 (SD 4.4).

Almost half (48.4%) of the physicians felt they had provided spiritual care to the last patient they attended at the end of life. Of these patients, 38.5% had dementia.

Table 2 shows the 30 items ranked by the proportions of physicians who included the items as belonging to spirituality at the end of life. It shows that all items included by more than 90% of the physicians (rank numbers 1-13 in Table 2) represented measurable and validated aspects of spirituality at the end of life. Of the items consistent with the spirituality literature, the least frequently included item concerned feeling disconnected (number 20) ; yet 73.4% of the physicians did include it. Further, almost all (95.4%) included one or more psychosocial items in their perception of spirituality, and 49.1% included at least one item on other issues.

Table 1: Participating elderly care physicians' characteristics (n = 284)

Age, mean (SD)	46.7 (9.5)	
Gender, % female	66.0	
Any additional training, %	26.0	
Geriatric Rehabilitation	7.5	
Psychogeriatric	6.0	
Palliative Care	10.7	
Ethics	2.5	
Experience as a certified elderly care physician, mean number of years (SD)	12.7 (8.4)	
Religious background % / Current denomination %		
Roman Catholic	43.3	10.7
Protestant	29.8	13.9
Evangelical	1.4	1.4
Islamic	1.1	0.7
Humanistic	2.1	2.8
Buddhist	1.1	0.7
Atheist	3.9	5.0
Agnostic	0.4	2.1
None	13.1	56.9
Other, such as anthroposophic, or several religions	4.0	2.8
Religiosity, mean sumscore Spiritual Beliefs and Practices Scale, (SD)	11.5 (4.4)	

Table 2: Physicians' perceptions of spirituality: items of measurable and validated aspects of spirituality at the end of life and non-spiritual items as reported in the literature (n = 284 physicians)

Item	Endorsed (%)	Missing* (n)	Spiritual Item +/-
1 Being supported by religion ^{Miyashita 2008}	98.9	0	+ S-CT- S-C
2 Believing in a supreme power ^{Hungelmann 1996}	96.8	0	+ S-CT
3 I feel peaceful ^{Steinhauser 2004}	96.8	1	+ S-WB

4 Talking with someone about religious issues ^{Hermann, 2006}	96.5	0	+ S-CT
5 Pray ^{Hermann 2006}	96.5	0	+ S-CT
6 Believing in an afterlife ^{Hungelmann 1996}	95.4	1	+ S-CT
7 Feeling that one is protected by a higher power beyond oneself ^{Myasita 2008}	95.1	0	+ S-CT
8 It is important to me that my life has meaning ^{Byock Merriman 2008}	94.0	0	+ S-WB
9 Reading a religious text ^{Hermann 2006}	93.3	0	+ S-CT
10 Dealing with unmet life goals ^{Rainbird 2005}	92.9	1	+ S-WB
11 Accepting your life situations ^{Hungelmann 1996}	92.2	1	+ S-WB
12 In case of dying suddenly today, feeling prepared to leave this life ^{Byock, Merriman 2008}	90.5	0	+ S-WB
13 Feeling that ones life was fulfilling ^{Miyashita 2008}	90.1	1	+ S-WB
14 Coping with feelings of sadness or grief ^{Rainbird 2005}	85.9	0	- PS
15 Coping with feeling useless ^{Rainbird 2005}	78.7	2	- PS
16/ 17* Having been able to say important things to those who are close ^{Steinhauser 2004}	78.4	1	+ S-WB
16/ 17* Wanting to share what you are going through with another person ^{Rainbird 2005}	78.4	1	- PS
18 Dealing with feeling afraid ^{Rainbird 2005}	78.3	3	- PS
19 Coping with fears about losing your independence ^{Rainbird 2005}	75.3	1	- PS

20	Feeling more disconnected from all things now than before illness <small>Byock, Merriman 2008</small>	73.4	2	+	S-WB
21	Dealing with feeling dependent on others <small>Rainbird 2005</small>	66.5	0	-	PS
22	Coping with having difficulty relaxing <small>Rainbird 2005</small>	65.6	2	-	PS
23	Receiving emotional support from friends and family <small>Rainbird 005</small>	65.5	0	-	PS
24	Dealing with maintaining relationships with friends <small>Rainbird 2005</small>	54.1	1	-	PS
25	Dealing with fears about the cancer spreading <small>Rainbird 2005</small>	53.2	2	-	PS
26	Trusting your physician <small>Miyashita 2008</small>	37.0	3	-	Other
27	Being involved with decisions about your medical treatment <small>Rainbird 2005</small>	33.7	2	-	Other
28	Dealing with concerns about your financial situations <small>Rainbird 2005</small>	21.6	2	-	Other
29	Getting adequate information from medical staff about your prognosis <small>Rainbird 2005</small>	18.3	0	-	Other
30	Coping with nausea and vomiting <small>Rainbird 2005</small>	16.5	0	-	Other

* Missing responses represent missing responses without comments or those with written comments such as “do not know”

+ 15 items representing measurable and validated aspects of spirituality at the end of life in literature:

S-WB Spiritual Wellbeing (peace/harmony/trust/hope/acceptance, purpose/meaning, connectedness, completion/fulfilment, positive affect/comfort)

S-CT Spiritual Cognitive Behavioral Context (spiritual beliefs, spiritual activities, spiritual relationships)

S-C Spiritual Coping

- 15 items representing non-spiritual aspects of quality of life at the end of life:

PS Psychosocial needs

Other Physical, medical-communicational, financial

‡ Exactly the same frequency

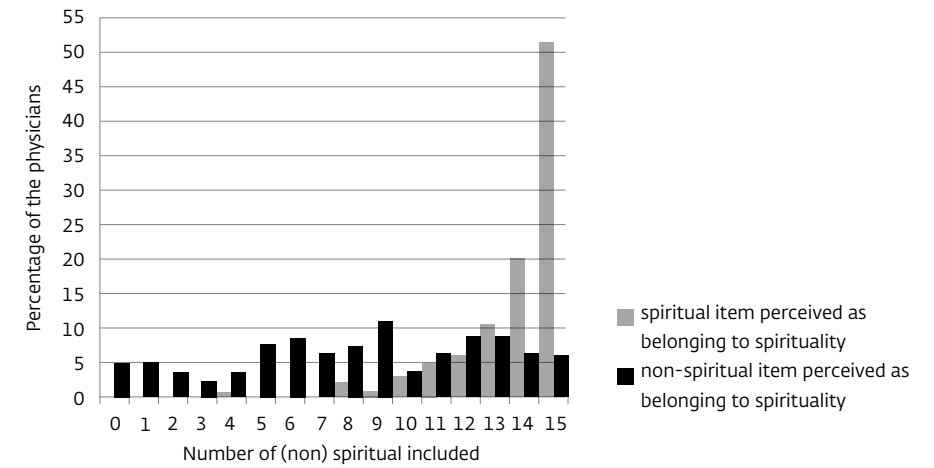


Figure 1. Distributions of spiritual and non-spiritual items included by the physicians as belonging to spirituality

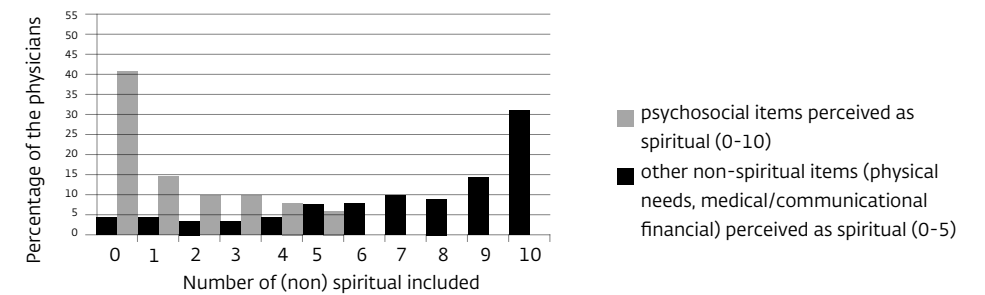


Figure 2. Distributions of psychosocial and other non-spiritual items included by the physicians as belonging to spirituality

Over half (51.8%) of the physicians included all 15 items that represented measurable and validated aspects of spirituality in the literature (Figure 1). Further, most others included almost all, the mean number being 13.8 of 15 items (SD 1.8). Nevertheless, most physicians were selective as only 4.9% included all 30 items. However, only 4.8% of the physicians did not additionally endorse any non-spiritual (quality-of-life) item, with a mean number of 8.3 such items additionally included, and with a larger standard deviation of 4.3. The mean total score for consistency with the literature was therefore 5.5 (13.8 minus 8.3), and it ranged between -7 and +14 (SD 3.9). Over half (54.3%) of the physicians indicated that they did not differentiate between spiritual and psychosocial needs in caring for the last resident who died. Physicians who did not differentiate between these needs included a higher number of non-spiritual items in their perception: mean 8.9 (SD 4.3) versus 7.5 (SD 4.2) for physicians who indicated they did differentiate between these needs.

Table 3: Adjusted association between physicians' perception of spirituality and the provision of spiritual end-of-life care

	Odds Ratio	95% C.I.
Physicians' perception of spirituality:		
Adjusted number of non-spiritual quality of life items included as spiritual, per item	1.33	1.11-1.60
Adjustments		
Age	1.00	0.96-1.05
Female gender	0.93	0.52-1.67
Additional training Palliative care	5.0	2.0-13
Experience as a certified elderly care physician, per year	1.00	0.95-1.05
No current religious denomination	0.77	0.42-1.4
Religiosity, sum score on the Spiritual Beliefs and Practices Scale, increment*	1.09	1.01-1.16
Total number of endorsed items (spiritual and non-spiritual)	0.90	0.77-1.04

In view of the distributions of the item scores of spiritual (skewed) and non-spiritual items as described above and reflected in Figure 1, we used the number of included non-spiritual quality-of-life items as the independent variable in the multivariable logistic regression. Unadjusted, we found a significant association between selecting more non-spiritual items and the reported provision of spiritual end-of-life care (OR 1.17, CI 1.10-1.24 per additional item included). In adjusted analyses, the association remained significant and was stronger (OR 1.33, CI 1.11-1.60 per additional item; Table 3). Further, more religious physicians were also more likely to report having provided spiritual end-of-life care (association with Spiritual Beliefs and Practice Scale: OR 1.09, CI 1.01-1.16 per point), as were those with additional training in palliative care (OR 5.0, CI 2.0-13). The association between the number of non-spiritual items included and having provided spiritual end-of-life care did not differ by physicians' score on the Spiritual Beliefs and Practice Scale (interaction term $p = 0.63$), nor by additional training in palliative care (interaction term $p = 0.37$). There was a modest correlation between the number of non-spiritual quality-of-life items included and religiosity ($r = 0.13$, $p = 0.03$). There was no significant correlation of the number of non-spiritual items included with: age, gender, additional training in palliative care, experience as a certified elderly care physician, and no current religious denomination.

DISCUSSION

Dutch elderly care physicians practicing in long-term care report providing spiritual care to almost half (48.4%) of the patients who are at the end of life. Their perception of spirituality included measurable and validated aspects of spirituality as reported in the literature, but overwhelmingly also included psychosocial aspects which the literature indicates as being non-spiritual quality-of-life issues: almost all (95.4%) included one or more psychosocial items in their perception of spirituality, and 49.1% included at least one other non-spiritual item (about physical, medical/communicational, or financial aspects). In a recent focus group study with Dutch elderly care physicians on spirituality and spiritual care at the end of life the participants expressed it is important to distinguish spiritual needs from psychosocial needs to adequately meet their needs.¹⁸ Rodin et al. showed the complex relationship between the spiritual dimension (spiritual wellbeing) and the other dimensions of care at the end of life.²⁷ They also underlined the importance of identifying the patient's specific needs to adequately relieve their specific distress at the end of life, thus emphasizing the importance of the distinction of the different needs, e.g. spiritual, psychosocial and physical. This study shows that our participants recognized the spiritual items described in the literature, but they also considered psychosocial items to be part of spirituality, and many may be aware they do not differentiate between them in practice, as shown by more than half of the physicians reporting not having differentiated between psychosocial and spiritual needs of the last resident who died. Therefore, physicians' training in distinguishing between spiritual, psychosocial and other needs of nursing home residents at the end of life may contribute to meeting their specific needs in multidisciplinary collaboration.

Religiosity, as measured with the Religious and Spiritual Beliefs and Practices Scale, was associated with the physicians' reports of having provided spiritual end-of-life care. More religious physicians may be more cognizant regarding spiritual end-of-life caregiving, as religious aspects of spirituality play an important role in their personal lives. The members of the professional organization for elderly care physicians in our survey were less religious than a random sample of members of the American Academy of Family Physicians in an older US study²⁶: mean sum score 11.5 (SD 4.1) vs 15.1 (SD 4.0). A US survey among physicians showed that more than half of the participants mentioned that their religious and spiritual beliefs influenced their practice of medicine, and the authors concluded that physicians should examine how their spiritual and religious beliefs might influence the manner in which they deliver care.²⁸

As end-of-life care for Dutch nursing home residents is provided by on-staff elderly care physicians, and as in most of the Dutch nursing homes the physicians are also responsible for the contents of the resident's care plan, they should include all the needs of the resident in this care plan, including spiritual needs at the end of life. The vocational training of Dutch elderly care physicians has a small curriculum on palliative care, but there is no attention for spiritual caregiving. The physicians who had two years of additional training in palliative care (with attention to all the domains of palliative care, including spiritual care) reported significantly more frequently that they provided spiritual end-of-life care, independent of their score on the Religious and Spiritual Beliefs and Practices Scale or having a current religious denomination. The regular palliative care curriculum in the training for elderly care physicians may be supplemented with learning to distinguish spiritual, psychosocial and other needs, and multidisciplinary collaboration on the specific

needs of the residents. It may also include attention to spirituality and spiritual caregiving in the form of reflecting on the perception of spirituality of the physician in relation to their spiritual caregiving. Benefits of extending training in spiritual care at the end of life as part of palliative care also involve a focus on what can be done, rather than on withholding of medical treatment only.

Limitations

The response (47.2%) was not high, but around half is common for physician survey studies.²⁹ We had no data on demographics of the members of the professional organization to compare with, but the response was not selective with regard to geographic distribution. The pre-structured item “In your opinion, spirituality at the end of life may comprise:” may have been inviting and resulted in a relatively high number of items included as belonging to spirituality. Further, although most physicians care for many dying patients in a year, for some physicians, the last resident may have been long ago and the response less precise.

CONCLUSION

A broad perception of spirituality that includes psychosocial needs and other non-spiritual aspects according to the literature, the physicians’ religiosity, and additional training in palliative care were associated with the provision of spiritual end-of-life care. Further research is recommended on the concept of spirituality, and also to study effects of multidisciplinary collaboration between the different disciplines on the quality of end-of-life care and the quality of dying and to identify best practices in spiritual caregiving at the end of life.

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REFERENCES

1. World Health Organization, definition palliative care: <http://www.who.int/cancer/palliative/definition/en/> (Last accessed January 2015)
2. Puchalski C, Ferrell B, Virani R, et al.: Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *J Palliat Med* 2009; 12: 885-904.
3. Hills J, Paice JA, Cameron JR, Shott S: Spirituality and distress in palliative care consultation. *J Palliat Med.* 2005;8(4):782-8.
4. Block SD: Perspectives on care at the close of life. Psychological considerations, growth, and transcendence at the end of life: the art of the possible. *JAMA* 2001; 22: 2898-905.
5. Cohen SR, Mount BM, Thomas JJ, Mount L: Existential well-being is an important determinant of quality of life. Evidence from the McGill Quality of life Questionnaire. *Cancer* 1996; 77: 576-586.
6. Edwards A, Pang N, Shiu V, Chan C: The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. *Palliat Med* 2010; 24: 753-770.
7. Phelps AC, Lauderdale KE, Alcorn S et al.: Addressing spirituality within the care of patients at the end of life: perspectives of patients with advanced cancer, oncologists and oncology nurses. *J Clin Oncol* 2012; 20: 2538-2544
8. 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; 53: 299-305.
9. Davies S, Seymour J: *Historical and policy contexts*. In: J. Hockley & D. Clark (eds) *Palliative Care for Older People in Care Homes*. Buckingham: Open University Press, 2002 pp. 4-33.
10. Broad JB, Gott M, Kim H et al.: Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *Int J Public Health* 2013; 2: 257-67.
11. Wallace M, O’Shea E: Perceptions of spirituality and spiritual care among older nursing home residents at the end of life. *Holistic Nurse Practice* 2007; 21: 285-289.
12. Daaleman TP, Williams CS, Hamilton VL, Zimmerman S: Spiritual care at the end of life in long-term care. *Med Care* 2008 Jan; 46: 85-91.
13. Gijsberts MJ, van der Steen JT, Muller M et al.: Spiritual End-of-Life Care in Dutch Nursing Homes: An Ethnographic Study. *J Am Med Dir Assoc* 2013; 14: 679-84.
14. van der Steen JT, Radbruch L, Hertogh CM et al.: White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* 2014; 28: 197-209
15. Schols JM, Crebolder HF, van Weel C: Nursing home and nursing home physician: the Dutch experience. *J Am Med Dir Assoc* 2004; 5: 207-12.
16. Koopmans RT, Lavrijsen JC, Zuidema SU: The Physician’s Role in Nursing Homes: The Dutch Solution. *Arch Intern Med* 2010; 170: 1406-1407.
17. Hoek JF, Ribbe MW, Hertogh CM, van der Vleuten CP: The specialist training program for nursing home physicians: a new professional challenge. *J Am Med Dir Assoc* 2001; 2: 326-330.
18. Gijsberts MJ, van der Steen JT, Muller MT et al.: Spiritual End-of-life care in nursing

- homes: An exploratory study among physicians. Presented at the 15th Congress of the International Psychogeriatric Association (IPA), the Hague, 6-9 September 2011. Congress program, page 93. Full paper is under review.
19. Gijssberts MJ, Echteled MA, van der Steen JT et al.: Spirituality at the end of life: conceptualization of measurable aspects-a systematic review. *J Palliat Med* 2011; 14: 852-63.
 20. Miyashita M, Morita T, Sato K et al.: Good death inventory: a measure for evaluating good death from the bereaved family member's perspective. *J Pain Symptom Manage* 2008; 35: 486-498.
 21. Hungelmann J, Kenkel-Rossi E, Klassen L, Stollenwerk R: Focus on spiritual well-being: harmonious interconnectedness of mind-body-spirit -- use of the JAREL Spiritual Well-Being Scale. *Geriatric Nursing* 1996; 17: 262-266.
 22. Steinhäuser KE, Clipp EC, Bosworth HB et al.: Measuring quality of life at the end of life: validation of the QUAL-E. *Palliat Support Care* 2004; 2: 3-14.
 23. Hermann, C: Development and testing of the spiritual needs inventory for patients near the end of life. *Oncol Nurs Forum* 2006; 33: 737-744.
 24. Byock IR, Merriman MP: Measuring quality of life with terminal illness: the Missoula-VITAS quality of life index. *Palliat Med* 1998; 12: 231-244.
 25. Rainbird KJ, Perkins JJ, Sanson-Fisher W: 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; 14: 297-306.
 26. Daaleman TP, Frey B: Spiritual and Religious Beliefs and Practices of Family Physicians, a National Survey. *J Fam Pract* 1999; 48: 98-104.
 27. Rodin G, Lo C, Mikulincer M, Donner A et al.: Pathways to distress: The multiple determinants of depression, hopelessness, and the desire for hastened death in metastatic cancer patients. *Soc Sci Med* 2009; 3: 562-569
 28. Curlin FA, Lantos JD, Roach CJ et al.: Religious characteristics of U.S. physicians: A National Survey. *J Gen Intern Med* 2005; 20: 629-634.
 29. Asch DA, Jedrzewski MK, Christakis NA: Response rates to mail surveys published in medical journals. *J Clin Epidemiol* 1997; 10: 1129-36.

SUB FINEM

En nu nog maar alleen
Het lichaam los te laten-
De liefste en de kinderen te laten gaan
Alleen nog maar het sterke licht
Het rode, zuivere van de late zon
Te zien, te volgen- en de eigen weg te gaan.
Het werd, het was, het is gedaan.

Maria Vasalis
In: *De oude kustlijn*
Uitgeverij G.A. van Oorschot

Chapter 8

GENERAL DISCUSSION

The aim of this thesis was to contribute to the understanding of the concept of spirituality at the end of life, to explore the perception of Dutch elderly care physicians of spirituality at the end of life and of their role in spiritual caregiving at the end of life in nursing homes, to explore current spiritual caregiving practices in Dutch nursing homes, and to identify facilitators for spiritual caregiving in nursing home residents suffering from dementia.

The accompanying research questions for this thesis were:

1. How can spirituality at the end of life be understood?
2. What is the perception of Dutch elderly care physicians of spirituality and their role in spiritual caregiving at the end of life in nursing homes?
3. What spiritual end-of-life care is provided to Dutch nursing homes residents, including residents suffering from dementia?
4. Which facilitators can be identified for spiritual caregiving in Dutch nursing home residents suffering from dementia?

In this final chapter the key findings of the studies as described in the chapters 2-8 will be summarized. Second, these findings will be interpreted and discussed. Subsequently, implications for practice and policy are considered, and finally, recommendations for research are discussed.

KEY FINDINGS

In the systematic review on ‘Spirituality at the end-of-life’, presented in chapter 2, we aimed to contribute to the understanding of the concept of spirituality at the end of life. The study resulted in a conceptual model of spirituality at the end of life. In this thesis, we present an adapted version of the model in figure 1, because the associations in this version of the model are especially supported by literature, and are particularly fitting the following description of the model, that was also presented in the original article in chapter two, thus making this version more specific than the more general associations in the original model.

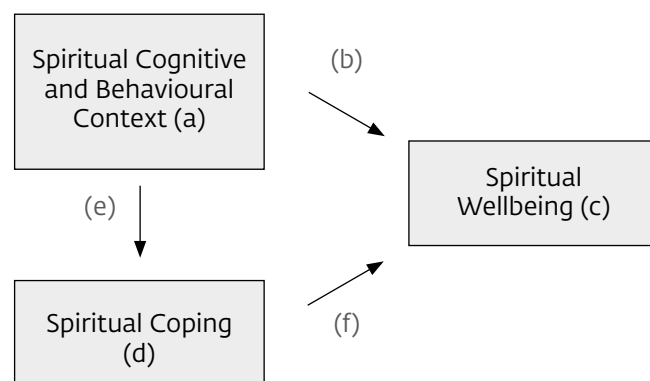


Figure 1. Conceptual model of spirituality at the end of life.

The model comprises three dimensions of spirituality at the end of life: spiritual wellbeing, spiritual cognitive and behavioural context, spiritual coping, and associations between these dimensions. We consider the dimension spiritual wellbeing as outcome in this model, comprising the categories meaning and purpose in life, connectedness, fulfilment, completion of life, peacefulness, acceptance and hope. The patients’ spiritual coping and their spiritual cognitive and behavioural context (the patients’ spiritual beliefs, spiritual activities such as meditation or praying, and relationships connected to their spirituality) may contribute to the spiritual wellbeing of the patient.

In this conceptual model, the patients’ spiritual resources (spiritual beliefs and relationships), spiritual appraisal processes and spiritual activities, are outlined as spiritual cognitive and behavioural context (a). A persons’ spiritual cognitive and behavioural context may directly contribute (b) to the patients’ spiritual wellbeing (c).^{1,2}

Spiritual coping (d) encompasses the entire range of human coping options, specifically incorporating spiritual resources (e).³ The patients’ spiritual beliefs also determine which spiritual coping strategies will be used (e) to promote spiritual wellbeing (e.g. meaning-making, acceptance and being at peace) (e).^{4,5} The patients’ spiritual coping may contribute to their spiritual wellbeing, as it is “an aid in meaning making ... and growth on a spiritual level” (f).⁴

Chapter 3 describes the focus group study with Dutch elderly care physicians, in which the physicians’ perception of spirituality at the end of life and of their role in spiritual caregiving at the end of life in nursing homes was explored. Their perception of spirituality comprised religious aspects (e.g. religious beliefs, attending mass, and the importance of a health care chaplain to obtain spiritual care), and also aspects of spiritual wellbeing (e.g. being at peace, experiencing harmony and meaning in life, having trust in an afterlife, the completion of life, and the acceptance of dying). The participants expressed a wide range of perceptions towards their role in assessing spiritual needs and the provision of spiritual care in nursing home residents at the end of life. The importance of the nurses in the assessment of spiritual concerns in residents was underlined, whereas collaboration with spiritual counsellors was often considered difficult. Participants attributed this to a tension between the spiritual counsellors’ professional confidentiality and openness in multidisciplinary collaboration. Spiritual care in dementia was considered difficult, because of the impossibility of (verbal) communication. However, religious rituals and spiritual artefacts facilitated assessing and addressing spirituality. Participants expressed lack of time and competence to be a barrier in assessing spiritual needs and providing spiritual care.

In chapter 4 the ethnographic study is presented, in which we observed spiritual caregiving at the end of life in a nursing home for residents suffering from dementia or from physical disabilities. Spiritual issues were not part of the formal care process: they were not discussed with residents or their loved ones, not reported in the care plan or medical chart, there was no communication between the physicians and the spiritual counsellor on spiritual issues of the residents. When the resident was dying the nurses started an informal (spiritual) care process, aimed at supporting the resident in his/her (spiritual) well-being, e.g. to die peacefully, to experience connectedness with loved ones, and to complete significant relationships, but this was not mentioned in the care plan or the medical chart. Nurses and physicians had their own subcultures in which behaviour of residents was given different meaning (depending on the frame of reference within this subculture), this appeared to be a hindrance to communication concerning the residence needs, including spiritual needs.

In chapter 5, caregiving at the end of life to nursing home residents with dementia was compared between anthroposophic and traditional nursing homes, using the “End-of-Life in Dementia” scales” (EOLD). One of the scales of the EOLD is The Comfort Assessment in Dying (CAD). This scale contains a subscale ‘wellbeing’, with three items that can be found in literature and measurement instruments on spirituality: serenity, peace, calm. The score on the subscale ‘wellbeing’ was significantly higher in the anthroposophic nursing homes than in the traditional homes. As anthroposophic nursing home care is a translation of the spiritual philosophy in the care process, this study raised questions on the generalizability of the results to nursing homes with other religious/spiritual orientations, as well as which aspects are facilitators in spiritual end-of-life care: person centred care, high quality of end-of-life care and/or palliative care (including spiritual care)? These issues were subsequently variables in the Dutch End Of Life in Dementia study.

In the Dutch End Of Life in Dementia study, presented in chapter 6, independent predictors of the providing of spiritual end-of-life care in dementia were identified, based on potential predictors referring to: high-quality, person-centred, and palliative care, as well as demographics. Independent predictors were: families satisfaction with physicians’ communication at baseline, and faith or spirituality having been very important to the resident, whether or not of importance to the physician. Also, female family care giving was an independent predictor. Palliative care indicators in this study were not predictive of spiritual end-of-life care (e.g. palliative care explicitly provided at location, palliation as the care goal, anticipating death and recognizing of dementia as a terminal disease). Physician-family communication upon admission may be important to optimize spiritual caregiving at the end of life.

Chapter 7 presents a survey with a representative sample of elderly care physicians on their perception of spirituality at the end of life and the association between this perception and the provision of spiritual care. The results show that almost all physicians recognize measurable and validated aspects of spirituality at the end of life, but most physicians include psychosocial aspects in their perception of spirituality, and to a lesser extent also include other aspects, such as physical, financial and communication on medical issues. A broader perception of spirituality, the physicians’ religiosity, and additional training in palliative care were significantly associated with spiritual caregiving at the end of life by physicians.

INTERPRETATION AND DISCUSSION OF THE RESULTS

Understanding of spirituality at the end of life

The model with the dimensions of spirituality at the end of life and their associations presented in chapter 2 (figure 1) may contribute to theoretical comprehension of the concept. The dimension spiritual coping appears to be understudied. This dimension of spirituality at the end of life was introduced by Kenneth Pargament. He performed ground breaking work on the association between spiritual coping and spiritual wellbeing in patients and described how patients incorporate their spiritual resources in these spiritual coping strategies. For example, reframing difficulties in positive spiritual terms, seeking support from people in the patients spiritual community, praying to emphasize the supporting

relationship with God, and meditation as a contribution to acceptance are examples of possible ways to incorporate aspects of the patients’ spiritual and cognitive context in their spiritual coping, that may contribute to their spiritual well-being. Further exploration of this dimension may be important to understand how people at the end of life may cope with spiritual distress.

How does the result of our review relate to other recent reviews on spirituality at the end of life? Our model contains three dimensions of spirituality at the end of life: spiritual wellbeing (meaning and purpose in life, connectedness, fulfilment, completion of life, peacefulness, acceptance and hope), spiritual cognitive and behavioural context (the patients’ spiritual beliefs, spiritual activities such as meditation or praying, and relationships connected to their spirituality), spiritual coping, and associations between these dimensions. We consider the dimension spiritual wellbeing as outcome in this model, to which patients’ spiritual coping and their spiritual cognitive and behavioural context may contribute.

In their conceptual analysis of spirituality at the end of life, Vachon et al⁶ distinguish 11 dimensions: meaning and purpose in life, self-transcendence, transcendence with a higher being, feelings of communion and mutuality, beliefs and faith, hope, attitude toward death, appreciation of life, reflection upon fundamental values, the developmental nature of spirituality, and the conscious aspect of the nature of spirituality. This last dimension is elucidated in the article as: ‘the conscious and reflected aspect of spirituality’ and as: ‘the reflective process associated with this experience also characterizes the conscious aspect of spirituality’. Therefore, in this study cognitive capacities are considered to be important in experiencing spirituality at the end of life,⁶ with categories as ‘self-transcendence’, ‘transcendence with a higher being’, and ‘the conscious aspect of the nature of spirituality’. This may consequently exclude many older patients with mild or more severe cognitive impairment from experiencing spirituality, spiritual well-being and receiving spiritual care.⁷ Therefore, a concept of spirituality at the end of life with an emphasis on cognitive appraisal may be less appropriate for the nursing home population, especially older people suffering from severe dementia.

In addition, two studies have explored the concept of spirituality at the end of life and the influence of culture on this concept. In a study on spiritual wellbeing in palliative care patients, Vivat et al.⁸ underlined the cultural specificity of this dimension of spirituality at the end of life. Selman et al. performed a systematic review on cross-culturally validated tools measuring spirituality in palliative care. They also developed a conceptual model of spirituality,⁹ with the dimensions: outlook on life, meaning or the search for meaning, connection to others, purpose, feeling at peace or at peace with God, life worth or value, and connection to God, spirit, or supernatural being. Most dimensions in the model from this cross-cultural study are also represented in the model represented in figure 1. However, the study by Selman et al. had “a central individual experience of illness of the patient”, but did not have a dimension of spiritual coping. Possibly, spiritual coping may also be a cultural sensitive dimension of spirituality at the end of life.

Dutch elderly care physicians’ perception of spirituality at the end of life

The perception of spirituality at the end of life that the participants reported in the focus group discussions (chapter 3), comprised many aspects of spiritual wellbeing and spiritual cognitive and behavioral context. Also, quantitative data were collected on the physicians’ perception of spirituality at the end of life in the survey study (chapter 7). The key findings

of the survey show that the participating physicians recognized almost all spiritual items according to literature, but almost all physicians also included one or more psycho-social items in their perception of spirituality and, almost half of the physicians included one or more items on physical, communicational and other issues. Apparently, physicians have difficulties in delimiting the dimension of spirituality at the end of life from the other dimensions of end of life care. The inter-relationship between the three dimensions of end of life care: the spiritual, psychosocial and physical dimension in end-of-life care is very complex.^{10,11} Therefore, several models concerning the inter-relationship between the physical, psycho-social and spiritual dimensions have been published in literature, aimed to a better understanding of this complex topic.^{12,13,14} The model by Stallwood and Stoll¹² is frequently used in publications on spiritual care at the end of life and nursing (figure 2).¹³ The outermost circle represents the physical body, the second circle depicts the psychosocial dimension. The innermost circle is described as spiritual. Regarding the interrelationships of the dimensions in the model, the physical dimension is considered to influence the psychosocial and spiritual dimensions.¹³ The inter-relationship between the spiritual and the psychological in this model is thus described: “it is true that many of the things associated with spirituality, such as our need to find meaning, purpose and fulfilment, are directly related to our psychological wellbeing”.¹³ This may explain that many physicians included psychosocial items in their perception of spirituality.

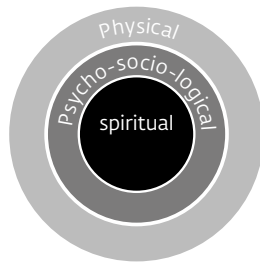


Figure 2. Conceptual model of the nature of man.
Stallwood and Stoll 1975

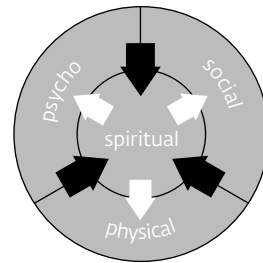


Figure 3. The position of spirituality. Relation between the spiritual and the physical, psychological, and social dimensions of human existence.
Leget C, Staps T et al., 2014

In the Dutch Guideline Spiritual Care in Palliative Care (figure 3),¹⁴ the spiritual dimension is also depicted as “the most intimate and concealed dimension: less measurable than the other three, but continually in a relationship of reciprocal influence with them”.¹⁶ However, the physical and the psycho-social are depicted in a similar relationship to the spiritual. Further study will be needed to attain a better understanding of the inter-relationship between the spiritual dimension and the psycho-social and physical dimensions of palliative care.

Dutch elderly care physicians' perception of their role in spiritual care-giving at the end of life

As for their role in spiritual caregiving, in chapter 3, some physicians in the focus group discussions expressed that they did not ask about spiritual issues in their nursing home patients at all, many physicians considered it difficult to address spiritual issues. This is consistent with a US study that also showed that physicians are not (trained to be) familiar with identifying and addressing psychosocial and spiritual issues at the end of life.¹⁵

In the survey in chapter 7, additional training in palliative care was associated with the provision of spiritual end-of-life care. Physicians that had a two-year additional training in palliative care (mostly attended by general practitioners and elderly care physicians) felt that they provided spiritual care significantly more often to their patients at the end of life. In this additional training, attention is paid to all the dimensions of palliative care, and learning how to pay attention to spiritual issues at the end of life is part of this training, thus facilitating the elderly care physicians to address spiritual issues.

Also, physicians' religiosity was associated with the provision of spiritual end-of-life care in the survey study. When religion is important to the physicians, they may be more focussed on spiritual issues of their patients.

Although many physicians stated they did not address spiritual issues, two studies from the patients' perspective, one in the US and one in Flanders, Belgium,^{16,17} showed that patients consider it important that their physicians ask about their spiritual coping and support mechanisms. In her PhD study ‘Spirituality at the end of life: art or science?’ Vermandere describes the discrepancy between the fact that most patients expect their health-care team to pay attention to the spiritual dimension of end-of-life care, while physicians and nurses often await their patients initiative to discuss the topic.¹⁷ Discussions between physicians and patients on spiritual issues may even lead to more appropriate medical advice and even lead to a change in medical decision and advance care planning.¹⁸

How could elderly care physicians be trained in exploring spiritual needs and/or spiritual resources in nursing home residents at the end of life? And learn to distinguish if those spiritual needs require professional support from a spiritual counsellor? In the report of the US Consensus Conference in the US on improving the quality of spiritual care as a dimension of palliative care,¹⁹ ‘taking a spiritual history’ is promoted, including the assessment of patient's beliefs and values, their spiritual strengths and spiritual distress. Screening instruments are available, which mostly include questions on religious affiliation and spiritual practices, and also touch upon aspects of spiritual well-being (e.g., meaning, importance of belief, sources of hope).¹⁹ The FICA instrument is the most frequently used screening instrument.^{20,21,22} A recent study in Flanders, Belgium showed that the questions of the FICA instrument could be feasible for the assessment of spirituality by general practitioners, provided that physicians could use these questions in a spontaneous conversation with the patient (instead of scoring items of an instrument).²³ This also applied to the use of the 5 questions from the ‘ars moriendi’ model (the ‘art of dying’ model),¹⁹ that was introduced in the Dutch guideline Spiritual Care in Palliative Care.¹⁴ The questions of this model have recently been used in a qualitative study in a hospital setting in the Netherlands²⁴ and an RCT in Belgium.¹⁹ Other instruments that have useful questions are the HOPE instrument²⁵ and the SPIRIT instrument.²⁶ As spirituality at the end of life is a culturally sensitive concept, further study is needed to examine if one of the instruments/model is more suitable for Dutch physicians.

Assessing spiritual needs and providing spiritual care in residents suffering from (advanced) dementia was considered specifically difficult by the participants of the focus group study, because of the impossibility of (verbal) communication with the residents on their spiritual needs. Visual symbols (religious artefacts) and rituals may help the residents suffering from dementia to connect to religious matters, thus contributing to their spiritual well-being.^{27,28} MacKinlay and Trevitt²⁹ also underline the role of artefacts and rituals to experience and express spirituality in dementia: symbols still retain their importance in dementia because they may convey (religious/spiritual) meaning. Religious symbols that were mentioned in chapter 3 are: images of Christ, the Virgin Mary and images of saints.

Spiritual caregiving at the end-of-life in Dutch nursing homes residents

One of the findings in the ethnographic study in chapter 4, was the informal spiritual caregiving by the nurses, that was provided to all the residents who died during the study. The nurses supported the residents to die peacefully, to experience connectedness with loved ones at the end of their lives, and to complete significant relationships. This spiritual caregiving was person-centred, and was guided by their understanding of the residents' life, their cognitive abilities, significant relationships, last wishes and spiritual resources. However, this spiritual support was not recognized as such, not by the nurses themselves, nor by the other members of the multidisciplinary team. It was not 'visible' to the rest of the multidisciplinary team, and was not acknowledged in the residents' care plan. Also, there was no multidisciplinary communication on the residents' spiritual needs and resources, including the spiritual counsellor. These results raise questions about if and how the lack of communication about spiritual end-of-life issues between disciplines, and the informal and formal care processes affects spiritual wellbeing. In the WHO definition of palliative care³² however there is an emphasis on multidisciplinary teamwork to address the needs of the patient: "the multidisciplinary approach allows the palliative care team to address physical, emotional, spiritual and social concerns that arise with advanced illness". Internationally, multidisciplinary teamwork on patients' spiritual issues is promoted, with the health care chaplain as integral part of the team,²¹ also in patients with dementia.³¹ This multidisciplinary approach is also promoted in the Dutch guideline of spiritual care in palliative care, in which the various disciplines each have their own expertise, role and task, the health care chaplain being the trained professional in spiritual care.¹⁶ The role of the different disciplines is described and referral to the spiritual counsellor in spiritual needs is promoted. In the nursing home in which the ethnographic study was performed, and probably in many other Dutch nursing homes the spiritual counsellor however did not collaborate with the multidisciplinary team on residents' spiritual issues at the end of life. Further study will be needed to explore if a multidisciplinary approach, in which the health care chaplain is part of the team and the spiritual issues are part of the residents' care plan, is an approach that is suitable for the Dutch situation, and if this approach would be beneficial towards the spiritual caregiving in nursing home residents.

Predictors for spiritual caregiving at the end of life in nursing home residents suffering from dementia

In the retrospective study on Dementia end of life care in chapter 5, caregiving in dementia at the end of life in anthroposophical and traditional nursing homes was compared using the End Of Life in Dementia scale (EOLD). The anthroposophical affiliation was

associated with more comfort in patients dying with dementia, including a significant higher score on the subscale Wellbeing, that consists of the items peace, serenity and calm. These are terms that represent spiritual wellbeing in literature on spirituality at the end of life. In the significant association between more spiritual wellbeing at the end of life and the religious affiliation of the nursing home, the affiliation of the nursing home may be regarded as a facilitator in spiritual care giving at facility (nursing home) level. But the anthroposophical nursing homes participating in this study may also have attracted nurses, physicians, therapists and residents that are specifically interested in anthroposophy and anthroposophical medicine and therapies. Therefore, the significantly higher spiritual wellbeing in residents may have been caused by different variables.

Subsequently, in the prospective Dutch End Of Life in Dementia study in chapter 6, the data analysis was based on variables (potential predictors) at facility level, physician level and resident / family level. The significant independent predictors in his study were: families' reports of faith or spirituality having been very important to the resident irrespective of the importance to the physician, families' reports of satisfaction with physicians' communication at baseline, and female family care giving.

When families explicitly report to the physician that the faith or spirituality has been very important to the resident, this knowledge may have been helpful to provide appropriate, patient-centered spiritual care, which is described by Hughes et al. as: "acknowledging and supporting spirituality, regard to overall quality of life and promoting dignity".³³

In the prospective Dutch End Of Life in Dementia study in chapter 6, families' reports of satisfaction with the physicians' communication was also an independent predictor. As several studies show, communication is decisive in assessing and distinguishing physical, psychosocial and spiritual issues at the end of life, and meeting needs of the patient.²⁶⁻³¹ Also, in the Dutch guideline on spiritual care in palliative care one of the conditions for the provision of spiritual care is the physicians' attention the physician has for the spiritual needs of the resident, by listening supporting, recognizing and screening of spiritual needs.¹⁶ These of course are communication skills. Specific training in communication skills to discuss spiritual issues at the end of life may be considered.

Potential palliative care indicators as defined in the study were unrelated to spiritual end-of-life care. These indicators were: palliative care explicitly provided at location, anticipating death of the resident, recognizing dementia as a terminal disease, and palliative care goal for the resident. It is remarkable that a palliative care goal does not result in attention to one of the dimensions of palliative care. In Dutch long-term care practice, not all physicians may have a clear view of what palliative care in dementia entails, especially the spiritual dimension of palliative care and the possibility of multi-disciplinary collaboration. In the Netherlands, there are no multidisciplinary specialist palliative care teams that explicitly help support end-of-life caregiving such as in Flanders^{34, 35}, or the US.³⁶ However, we do not know if multidisciplinary teamwork in the Netherlands would lead to more and better attention for spiritual issues. This could be a topic for further study.

Therefore, understanding the importance of spirituality to resident with dementia appears to be an important contribution to patient-centred spiritual care giving. Also, communications skills of physicians (at baseline) may also improve spiritual caregiving. Further study on multidisciplinary teamwork as described in guidelines on spiritual care in palliative care is needed to examine if this may improve spiritual caregiving at the end of life to residents with dementia in the Netherlands and in Dutch nursing homes.

PRACTICE AND POLICY RECOMMENDATIONS

The first practice recommendation concerns possible components for spiritual interventions. The results of the different studies in this thesis provide several components for spiritual interventions, that may contribute to the practice of spiritual caregiving, and consequently to spiritual wellbeing and quality of life of the nursing home residents. These components include: attention for spiritual beliefs, especially if these beliefs have been very important to the nursing home resident, and attention for spiritual relationships, including the spiritual relationships that existed before the residents' admission to the nursing home. These aspects may be specifically important for physicians, first to understand the residents' spiritual resources at the end of life, and they may also contribute to the understanding of the residents' preferences in advance care planning. Also, spiritual activities may contain core components for spiritual intervention, such as praying, attending mass, singing hymns, bible reading, and (personal) spiritual rituals, as well as attention for artefacts that may indicate the spiritual affiliation of the resident and offer, also in dementia. In addition, attention for peacefulness at the end of life, connectedness with loved ones, the completion of life with attention for unfinished business, acceptance of death, a sense of fulfilment in life, and also support for spiritual coping may be a core component for spiritual interventions.

The second recommendation concerns multidisciplinary collaboration. The results in chapter 3 and 4, the focus group study and the ethnographic study, show that multidisciplinary collaboration is still challenging, also with spiritual counsellors. However, the conditions for multidisciplinary collaboration in Dutch nursing homes are often favourable, with on staff physicians, psychologists, therapists, and many nursing homes also employ staff spiritual counsellors that are specifically trained to address spiritual needs of nursing home residents. Best practices in multidisciplinary caregiving may be found in Belgium and the US. In Belgium, palliative care is organized in a multidisciplinary way: mobile palliative home teams support general practitioners, and hospitals have palliative support teams and often palliative units.³⁴ In nursing homes, one of the physicians and head nurses have a leading role in the provision in palliative care,³⁴ and at least one member of staff is responsible for the coordination of palliative care.³⁵ In the US, palliative care in nursing homes is provided by Medicare hospice care, and collaboration between the hospice care teams and nursing home teams is promoted to provide good end of life care in nursing homes, also in dementia³⁶. The results of this thesis show that in many nursing homes the Dutch multidisciplinary guideline on spiritual care in palliative care is still ahead of reality. The first best practices on palliative care in dementia have been published in the Netherlands,³⁷ which may be inspirational to further development of multidisciplinary palliative care in Dutch nursing homes, including spiritual care.

The third recommendation concerns the skills of the elderly care physicians in addressing spirituality at the end of life. The studies in chapter 3, 4 and 7 (the focus group study, the ethnographic study and the survey among elderly care physicians) show, that physicians do not always assess spiritual needs and provide spiritual care to their residents. However, the study by Vermandere shows that patients do not only want their physicians to ask about their spiritual needs, but the information may also be important in discussions on advance care planning. Understanding the residents spirituality may put these discussions

in a different perspective, and they may go further than a conversation on resuscitation or hospitalization. Such discussions may also include what is necessary for the resident to complete his or her life. Thus, they may be more positive and meaningful, and may also contribute to the spiritual wellbeing of the resident. Additional training of elderly care physicians in addressing spiritual issues at the end of life may support elderly care physicians in their communication skills on spiritual issues at the end of life.

The last recommendation concerns the bridging of communication challenges between the different disciplines with their own languages. The results of the ethnographic study in chapter 4 showed that different professional disciplines appear to operate in separate subcultures. In the different languages these subcultures employ, important information on the residents' situation and problems may get lost to other disciplines. In addition, participants in the focus group study in chapter 3 described that exchanging information between physician and spiritual counsellor is often difficult. It may be a good investment for all the members in the multidisciplinary team to realize that other disciplines may have valuable information, and that actively informing after this information and the importance of this information means for the other disciplines may lead to better support of the nursing home resident and their loved ones at the end of life.

RECOMMENDATIONS FOR FUTURE RESEARCH

Spirituality at the end of life is a complex and cultural sensitive concept. In chapter 2 we developed a model on spirituality at the end of life, based on empirical research. Further research on this concept is needed, and a validation study in one or more countries of the model on spirituality presented in chapter 2 may be supportive to the understanding of this complex and cultural sensitive concept.

As described in the practice recommendations, the results of the different studies in this thesis provide components for spiritual interventions, that may contribute to the practice of spiritual caregiving, and consequently to spiritual wellbeing and quality of life of the nursing residents. These include: attention for spiritual beliefs, especially if these beliefs have been very important to the nursing home resident, and attention for spiritual relationships, including the spiritual relationships that existed before the residents' admission in the nursing home. Also, spiritual activities may contain core components for spiritual intervention, such as praying, attending mass, singing hymns, bible reading, and (personal) spiritual rituals, as well as attention for artefacts that may indicate the spiritual affiliation of the resident and offer, also in dementia. In addition, attention for peacefulness at the end of life, connectedness with loved ones, the completion of life with attention for unfinished business, acceptance of death, a sense of fulfilment in life, and also support for spiritual coping may be a core component for spiritual interventions. To determine which of these components may be considered as core components for spiritual interventions, a Delphi study with experts from different professional disciplines (spiritual counsellors, nurses, physicians, psychologists, researchers, nursing home residents) may be performed to prioritize the different components of spiritual interventions.

Another interesting topic of further research, that recurred in two studies was the collaboration and communication on spirituality and spiritual issues in the multidisciplinary

team. In the focus group study (chapter 3) physicians considered the nurses to be very important in assessing spiritual issues in nursing home residents, and this concurred with observations in our ethnographic study, presented in chapter 4. However, the observations and interventions of the nurses did not reach the physician, nor other members of the multidisciplinary team. Also, in the focus group study the physicians had various experiences in the collaboration and communication with health care chaplains. It is yet unclear whether a lack of communication between the health care chaplain and the multidisciplinary team is a hindrance to spiritual care giving at the end of life to Dutch nursing home residents. However, the Dutch guideline for Spiritual Care in Palliative Care promotes collaboration in a multidisciplinary team with the health care chaplain as the expert on spiritual caregiving. Possibly there are settings in the Netherlands that have such a multidisciplinary team, that would provide an opportunity to study if and how this collaboration improves spiritual caregiving to nursing home residents. An ethnographic study would be a suitable research method to explore this topic.

The results of the Dutch End Of Life in Dementia study presented in chapter 6, show that good communication at baseline with the physician was an independent predictor for spiritual caregiving at the end of life. In the survey presented in chapter 7, several physicians included items on communication on medical issues in their perception of spirituality at the end of life. In the Dutch Guideline Spiritual Care in Palliative Care is also described that the physician are expected to assess the residents' spiritual resources and spiritual needs, and to refer to a spiritual counsellor when this may be beneficial to the resident. Therefore, supporting physicians' skills in addressing spiritual issues may be a practical way to improve spiritual caregiving at the end of life. In the focus group study in chapter 3, many physicians stated that they did not feel competent to do so. To explore if additional training for physicians is beneficial to spiritual support for nursing home residents, a pilot study during the vocational training of elderly care physicians may be performed, in which a part of the physicians receives the traditional training, and another part receives additional training in screening spiritual issues (using items from the FICA instrument and/or questions from the 'ars moriendi model' in natural conversations with nursing home residents and/or their relatives) and addressing spiritual needs. Subsequently, in this pilot study, the end of life caregiving by elderly care physicians, including spiritual caregiving at the end of life, may be explored to see if this additional training was beneficial to the physicians' attention toward spiritual issues in residents at the end of life and to satisfaction with spiritual caregiving in residents and their loved ones. Interviews may be a suitable research method to study the results of additional training.

The physicians' perception of spirituality at the end of life in the focus group study presented in chapter 3, concurred with recent literature on the concept of spirituality at the end of life. However, in the survey study, presented in chapter 7, many physicians had a broader perception of spirituality, including psychosocial aspects, and to a lesser degree, physical aspects and communication on medical issues. Further study on spirituality at the end of life and its relationship to the psycho-social and physical, the other dimensions of palliative care, may provide insight in this subject and be helpful to fully support patients and nursing residents at the end of life. A Delphi study with experts from different professional disciplines (spiritual counsellors, physicians, psychologists, psychiatrists and researchers) may be performed to contribute to understanding of the distinction between spiritual dimension and the other dimensions of palliative care.

In the Dutch End Of Life in Dementia study in chapter 6 palliative care was not an independent predictor for provision of spiritual care. In recent years, attention to palliative care in dementia is increasing, internationally as well as in the Netherlands. Further study on best practices may be performed to examine how people with dementia may be supported in their spiritual wellbeing, including attention for the use of visual symbols and rituals.

Spirituality is still the least studied dimension of palliative care. Further research is needed on the concept of spirituality and its dimensions, and on its relationship with the psychosocial and physical dimension of palliative care. This may lead to better understanding of the spiritual dimension and subsequently better assessment of spiritual needs and better provision of spiritual care at the end of life, also in nursing homes. Elderly care physicians may benefit from additional training in 'taking a spiritual history' and addressing spiritual needs. Best practices on spiritual caregiving at the end of life in nursing homes may be identified, including multidisciplinary collaboration and assessing spiritual needs, and spiritual caregiving in dementia to best meet the spiritual needs at the end of life in nursing home residents and their loved ones.

REFERENCES

1. Davis CG, Nolen-Hoeksema S, Larson J. Making sense of loss and benefiting from the experience: two construals of meaning. *J Pers Soc Psychol* 1998 Aug;75(2):561-74.
2. Ameling A, Povilonis M. Spirituality, meaning, mental health, and nursing. *J Psychosoc Nurs Ment Health Serv* 2001 Apr;39(4):14-20.
3. Pargament KI. *The Psychology of Religion and Coping: Theory, Research, Practice*. 1997. Guilford Press, New York.
4. Pargament KI, Koenig HG, Tarakeshwar N, Hahn J. Religious coping methods as predictors of psychological, physical and spiritual outcomes among medically ill elderly patients: a two-year longitudinal study. *J Health Psychol* 2004 Nov;9(6):713-30.
5. Dull VT, Laurie A, Skokan LA. A Cognitive Model of Religion's Influence On Health. *J Soc Issues* 1995 51(2) 49-64.
6. Vachon M, Fillion L, Achille M. A conceptual analysis of spirituality at the end of life. *J Palliat Med* 2009;12:53-59.
7. van der Steen JT, Gijsberts MJ, Echteled MA, Muller MT, Ribbe MW, Deliens L. Defining spirituality at the end of life. *J Palliat Med* 2009 Aug;12(8):677.
8. Vivat B, Young T, Efficace F, Sigurdadóttir V, Arraras JI, Ásgeirsdóttir GH, Brédart A, Costantini A, Kobayashi K, Singer S. Cross-cultural development of the EORTC QLQ-SWB36: a stand-alone measure of spiritual wellbeing for palliative care patients with cancer. ; EORTC Quality of Life Group. *Palliat Med* 2013 May;27(5):457-69.
9. Selman L, Harding R, Gysels M, Speck P, Higginson IJ. The measurement of spirituality in palliative care and the content of tools validated cross-culturally: a systematic review. *J Pain Symptom Manage* 2011 Apr;41(4):728-53.
10. Sulmasy DP. A biopsychosocial-spiritual model for the care of patients at the end of life. *Gerontologist* 2002 Oct;42 Spec No 3:24-33.
11. Rodin G, Lo C, Mikulincer M, Donner A, Gagliese L, Zimmermann C. Pathways to distress: the multiple determinants of depression, hopelessness, and the desire for hastened death in metastatic cancer patients. *Soc Sci Med* 2009 Feb;68(3):562-9.
12. Stallwood J, Stoll R. *Spiritual dimensions of nursing practice*. In: Beland I, Passos J. Clinical Nursing. 1975. New York, Macmillan
13. McSherry W. *Making sense of spirituality in nursing and health care practice, an interactive approach*. London, 2006, Jessica Kingsley Publishers.
14. Dutch Guideline Spiritual Care in Palliative Care: <http://www.oncoline.nl/spiritual-care> (Last accessed February 2015)
15. Chibnall JT, Bennett ML, Videen SD, Duckro PN, Miller DK. Identifying barriers to psychosocial spiritual care at the end of life: a physician group study. *Am J Hosp Palliat Care* 2004 Nov-Dec;21(6):419-26.
16. Hebert RS, Jenckes MW, Ford DE et al. (2001). Patient Perspectives on Spirituality and the Patient-physician Relationship. *J Gen Intern Med* 2001;16, 685-692.
17. Vermandere M. *Spirituality at the end of life: art or science?* Thesis, Leuven 2014.
18. McCord G, Gilchrist VJ, Grossman SD, King BD, McCormick KE, Oprandi AM, Schrop SL, Selius BA, Smucker DO, Weldy DL, Amorn M, Carter MA, Deak AJ, Hefzy H, Srivastava M. Discussing spirituality with patients: a rational and ethical approach. *Ann Fam Med* 2004 Jul-Aug;2(4):356-61.
19. Puchalski C, Ferrell B, Virani R, Otis-Green S, Baird P, Bull J, M.A., Chochinov H, George Handzo G, Nelson-Becker H, Prince-Paul M, Pugliese K, Sulmasy D. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *J Palliat Med* 2009;12:885-904.
20. Puchalski C, Romer AL: Taking a spiritual history allows clinicians to understand patients more fully. *J Palliat Med* 2000;3:129-137.
21. Puchalski CM: Spiritual assessment in clinical practice. *Psychiatr Ann* 2006;36:150.
22. Puchalski CM. The FICA Spiritual History Tool #274. *J Palliat Med*. 2014 Jan;17(1):105-6.
23. Vermandere M, Choi YN, De Brabandere H, Decouttere R, De Meyere E, Gheysens E, Nickmans B, Schoutteten M, Seghers L, Truijens J, Vandenberghe S, Van de Wiele S, Van Oevelen LA, Aertgeerts B. GPs' views concerning spirituality and the use of the FICA tool in palliative care in Flanders: a qualitative study. *Br J Gen Pract* 2012 Oct;62(603):e718-25.
24. Voskuilen JJ. *Levensvragen van palliatieve patiënten en het Ars moriendi model; Een kwalitatief onderzoek naar de betekenis die palliatieve patiënten geven aan de thema's van het Ars moriendi model*. 2012 Emmerich-Vrasselt
25. Anandarajah G, Hight E: Spirituality and medical practice: Using the HOPE questions as a practical tool for spiritual assessment. *Am Fam Physician* 2001;63:81-89.
26. Maugans TA: The SPIRITUAL history. *Fam Med* 1996;5:11-16.
27. Buckwalter GL. Addressing the spiritual and religious needs of persons with profound memory loss. *Home Healthc Nurse* 2003; 21:20-24.
28. van der Steen JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, Francke AL, Jünger S, Gove D, Firth P, Koopmans RT, Volicer L; European Association for Palliative Care (EAPC). White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med*. 2014 Mar;28(3):197-209.
29. MacKinlay EB, Trevitt C. Spiritual care and ageing in a secular society. *Med J Aust* 2007 May 21;186(10 Suppl):74-6.
30. WHO definition of spiritual care: <http://www.who.int/cancer/palliative/definition/en/> 2002 (Last assessed February 2015)
31. Hughes C, Lloyd Williams M, Sachs G. *Supportive Care for the person with Dementia*. 2010, Oxford University Press. ISBN 978-0-19-955413-3
32. De Gendt C, Bilsen J, Stichele RV, Deliens L. Advance care planning and dying in nursing homes in Flanders, Belgium: a nationwide survey. *J Pain Symptom Manage* 2013 Feb;45(2):223-34.
33. Li Q, Zheng NT, Temkin-Greener H. Quality of end-of-life care of long-term nursing home residents with and without dementia. *J Am Geriatr Soc* 2013 Jul;61(7):1066-73.
34. Palliative care in Belgium: http://ec.europa.eu/chafea/documents/news/Assessing_Organisations_to_Improve_Palliative_Care_in_Europe.pdf (Last assessed February 2015)
35. Palliative care in nursing homes in Belgium: http://health.belgium.be/eportal/Aboutus/crossborder_healthcare/foreignvisitors/providers/Healthcare-facility-standards/Palliative-care-structures/19089858_EN?ie2Term=elderly&ie2section=83#.VJaEzBsA (Last assessed February 2015)
36. Stevenson DG, Bramson JS. Hospice care in the nursing home setting: a review of the literature. *J Pain Symptom Manage* 2009 Sep;38(3):440-51.
37. Best practices palliative care in dementia in the Netherlands: http://www.zorgvoorbeter.nl/docs/PVZ/vindplaats/Dementie/Handreiking_Palliatieve_Zorg_bij_dementie.pdf (Last assessed February 2015)

Summary

A recent study in over 21 countries shows that almost a fifth of all deaths in older people occur in nursing homes. In the UK, Belgium and the Netherlands this figure is even higher: up to a quarter of older people die in nursing homes. Although the landscape of caregiving at the end of life in the Netherlands is currently being transformed, whereby it is the intention to allow people to live in their own house as long as possible, for many people the nursing home will still be the place where they will receive care at the end of life. For this reason, it is important that there is good end of life care for these nursing home residents, which should also include good spiritual care.

Palliative care is rooted in and developed from the pioneering work of Dame Cicely Saunders. The current definition of palliative care by the World Health Organization dates from 2002: "Palliative care is 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." Although the spiritual dimension has been one of the dimensions of palliative care for more than a decade, it is still the least developed one. However, there has been an increasing awareness of the importance of spiritual care at the end of life in the last decades, resulting in both an inclusion of spiritual care as a dimension of palliative care, and in an increasing number of studies on spirituality and spiritual caregiving at the end of life.

'Spirituality' however is very difficult to define, leading to variable understandings. In 2009, an important consensus conference in the US on improving the quality of spiritual care as a dimension of palliative care was held, in which experts with different backgrounds (physicians, nurses, spiritual counsellors, and researchers) achieved consensus on a definition of spirituality and recommendations on assessing spiritual needs and providing spiritual care. Spirituality was defined here as follows: "the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred."

In the Netherlands, the book on Guidelines in Palliative Care also includes the Dutch Guideline Spiritual Care in Palliative care. In this guideline, spirituality is described as: “the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.” Spirituality is also viewed as multidimensional, whereby the following dimensions are distinguished: 1- existential challenges 2- value based considerations and attitudes, and 3- religious considerations and foundations.

In the Netherlands, medical care in nursing homes is mostly provided by on-staff elderly care physicians. In addition to direct medical care, the physician is also responsible for the content of the resident’s care plan in most cases, wherein all the needs, including spiritual needs, should be represented, as well as the manner in which and by whom they are addressed.

Many studies on the physicians’ role in spiritual caregiving originate from Northern America. In these studies, physicians appear to be relatively unfamiliar with recognising and addressing questions concerning spirituality, although patients pose these questions. And even though the importance of spiritual care has been recognized more and more by physicians during the last decades, including spiritual care at the end of life, most physicians do not inquire about religion or spirituality until the patient is dying. Lack of time and lack of training are often mentioned by physicians as barriers. Spiritual issues are often not recognized and addressing spiritual needs is often not considered as the physicians’ responsibility. It is unclear if the results of these Northern American studies can be extrapolated to the Dutch situation, as the United States can be considered as a religious country and most citizens are church members, as opposed to the Netherlands, which is often regarded as a typical West-European secularized country.

Could spirituality also be important at the end of life for people with dementia? An important question, as a 25% of people aged 85 years and older die with dementia, and almost half of the nursing home residents suffer from dementia. Spirituality in dementia is still an understudied topic. It is unclear if and how (Dutch) nursing home residents with dementia receive spiritual care at the end of life, and if facilitators can be identified for the provision of spiritual care at the end of life in Dutch nursing home residents with dementia.

This thesis therefore aims to contribute to a better understanding of the concept of spirituality at the end of life, and to explore elderly care physician’s perceptions of spirituality at the end of life and of their role in spiritual caregiving at the end of life in nursing homes. It also aims to explore current spiritual caregiving practices in Dutch nursing homes, and tries to identify facilitators for spiritual caregiving in Dutch nursing home residents with dementia.

Accordingly, the main research questions for this thesis are:

1. How can spirituality at the end of life be understood?
2. What is the perception of Dutch elderly care physicians of spirituality and of their role in spiritual caregiving at the end of life in nursing homes?
3. What spiritual end-of-care is provided to Dutch nursing homes residents, including residents suffering from dementia?
4. Which facilitators can be identified for spiritual caregiving in Dutch nursing home residents suffering from dementia?

Mixed methods design

As the main research questions differ in nature, a variety of qualitative and quantitative research methods were used.

1. To answer the first research question, a **systematic review** on ‘Spirituality at the end-of-life’ was performed. A systematic review provides an overview of information on ‘spirituality at the end of life’, as it locates, appraises and synthesises the evidence from individual studies relevant to the research question and is conducted according to explicit and reproducible methodology.
2. To answer the second research question, we performed a **focus group study** among elderly care physicians to explore how they perceive spirituality and their role in spiritual caregiving at the end of life in nursing homes. This qualitative research method allows studying and clarifying topics through interaction between the participants. To study if these results could be generalized, items on spirituality and the role of the physician in spiritual caregiving were also represented in a nationwide **survey** in a representative sample of elderly care physicians.
3. To answer the third research question, an **ethnographic study** was performed to explore the actual practice of spiritual care at the end of life on two wards in a Dutch nursing home: one ward with residents with dementia, and one with residents with physical disabilities. Ethnography is the study of people and culture and offers an opportunity to uncover (underlying) behaviour and interactions of which the participants are unaware, providing rich, holistic insights into views and actions.
4. To answer the fourth research question, data from two quantitative studies were analysed. The first is a **retrospective study**, in which end of life care (including spiritual aspects) in both anthroposophic and traditional nursing homes to residents with dementia was compared, using the “End-of-Life in Dementia scales” (EOLD). In the second study we used data that were collected in the **prospective** Dutch End of Life in Dementia (DEOLD) study to identify independent predictors for the providing of spiritual end-of-life care in dementia were identified.

Chapter 2 describes the results of a **systematic review** on ‘Spirituality at the end-of-life’, in which we aimed conceptualize spirituality at the end of life by identifying dimensions of spirituality at the end of life, based on an analysis of items of instruments that measure spirituality in end-of-life populations. In 36 articles that met the inclusion criteria we identified 24 instruments. Nine instruments had adequate content validity. All the items of these nine instruments were used to identify dimensions of spirituality. To adequately represent these items to describe the relationships between the dimensions, a model was constructed. This model distinguishes the dimensions of Spiritual Well-being (e.g. peace, trust, hope, acceptance, purpose, meaning, connectedness, fulfilment, comfort), Spiritual Cognitive Behavioural Context (Spiritual Beliefs, Spiritual Activities and Spiritual Relationships), and Spiritual Coping, and also indicates relationships between the dimensions. The dimension Spiritual Well-Being is considered as outcome, to which Spiritual Coping, as well as Spiritual Beliefs, Spiritual Activities and Spiritual Relationships may contribute.

This model may help researchers to plan studies and to choose appropriate outcomes, and assist caregivers in planning spiritual care.

In **Chapter 3** we explored how Dutch elderly care physicians view an experience spiritual caregiving at the end of life in nursing homes through **focus group study**. Three focus groups were organized, each with 6 participants. To allow for sufficient variability in perceptions and opinions we recruited physicians with differing religious backgrounds, professional interests and experience. The discussions focussed on the following topics: (1) spirituality and spiritual wellbeing at the end of life, (2) the role of the elderly care physician in spiritual caregiving at the end of life, for residents with physical disabilities and residents with dementia, and (3) barriers and facilitators in providing spiritual care at the end of life. The findings indicate that participants perceived spirituality primarily as religion, though aspects that are defined as spiritual wellbeing in literature were also mentioned after further reflection, such as being at peace, harmony, trust in an afterlife, the completion of life and meaning. Certain physicians did not feel directly responsible for spiritual caregiving, and lack of expertise and time were mentioned as barriers. Communication with spiritual counsellors was considered to be complex. Difficulty of verbal communication was perceived as a barrier in assessing spiritual needs and providing spiritual care to residents with dementia. Participants however described how religious artefacts were helpful in spiritual caregiving and how religious rituals supported residents in their spiritual wellbeing. Therefore, asking the resident about the meaning of their religion could provide important information to start a conversation on spiritual issues and for appropriate spiritual care giving. Training programs may be developed to support physicians in addressing spiritual issues. Spiritual rituals and artefacts, as well as spiritual reminiscence may facilitate nursing home residents with dementia in experiencing in their spirituality.

Chapter 4 describes an **ethnographic study** in a Dutch nursing home, in which the provision of spiritual care at the end of life to residents with physical disabilities and with dementia was explored, as well as the collaboration and communication between the different professionals on this spiritual end-of-life caregiving, with a specific focus on the role of the elderly care physician. The study was conducted by two researchers, on a psychogeriatric unit (mostly residents with dementia) and a somatic unit for residents with physical disabilities. The findings showed that physicians did not actively address spiritual issues, nor was it part of the official job of care staff. There was no communication observed between the physicians and the spiritual counsellor. However, when a resident was about to die, the nurses did start an informal care process, aimed at (spiritual) well-being, including cuddling of the resident, and with attention for the completion of life with his/her loved ones, and for rituals and music. This was however not mentioned in the care plan or the medical chart. The nurses even took the time out to support residents outside of their professional role in their spare time. Furthermore, their appeared to be differing occupational subcultures, (i.e. a nurses' subculture and a physicians' subculture), wherein the behaviour of residents was understood differently and given a different meaning, depending on which frame of reference was used. The findings raise questions with regard to the lack of communication between disciplines about spiritual end-of-life care, and how informal and formal care processes might affect spiritual wellbeing of nursing home residents at the end of life.

Chapter 5 presents the results of a quantitative **retrospective study**, in which we explored if and how the philosophy of a nursing home affects the quality of life and satisfaction with care in nursing home residents with dementia. We compared end of life care (including spiritual aspects) in two anthroposophic and two traditional nursing homes

to residents with dementia, using the "End-of-Life in Dementia scales". Six weeks after a resident of a psychogeriatric nursing home unit had passed away, the resident's proxy (primary contact person) would receive a letter from the researcher asking whether he/she was willing to participate in this study. If they consented, the EOLD questionnaire was sent to the respondent, to which several questions about characteristics of the resident and the respondent had been added. Of the 60 resident's proxies that were approached, 34 participated in the study (57%). The results showed that there was no difference in mean Satisfaction With Care scale scores between both types of nursing homes. However, the anthroposophic nursing homes had significantly higher scores on the 'Symptom Management' and 'Comfort Assessment in Dying' scales and on its subscale wellbeing. The subscale wellbeing comprises three items that were also found in the literature on spirituality (and in subsequent instruments to measure it), as terms that refer to spiritual wellbeing: serenity, peace and calm. The results suggest that death with dementia was more favourable in anthroposophic nursing homes than in regular homes. Further prospective research is needed to study how specific philosophies are actually translated into daily nursing home practice, including decision making in multi-disciplinary teams, family consultation, and complementary non-pharmacological therapies.

In **Chapter 6** the results from the quantitative **prospective Dutch End of Life in Dementia study** are presented, in which we aimed to examine predictors of the provision of spiritual end-of-life care in dementia as perceived by physicians coordinating the care. We used data of the Dutch End of Life in Dementia study (2007–2011), whereby data were collected prospectively in 28 Dutch long-term care facilities. The outcome of Generalized Estimating Equations regression analyses was whether spiritual care was provided shortly before death as perceived by the on-staff elderly care physician responsible for end-of-life care (last sacraments or rites or other spiritual care provided by a spiritual counsellor or staff). Potential predictors were indicators of high-quality, person-centered, and palliative care, demographics, and some other factors supported by the literature. According to the physicians, spiritual end-of-life care was provided shortly before death to 20.8% of the residents. Independent predictors of spiritual end-of-life care were: families' satisfaction with physicians' communication at baseline, and faith or spirituality very important to resident whether of importance to the physician. Further, female family caregiving was an independent predictor. The results show that palliative care indicators were not predictive of spiritual end-of-life care; palliative care in dementia may need better defining and implementation in practice. Physician-family communication upon admission may be important to optimize spiritual caregiving at the end of life.

Chapter 7 describes the results of a cross sectional **survey** with 642 elderly care physicians, in which their perception of spirituality at the end of life, their provision spiritual care at the end of life, and the relation between the physician's perception of spirituality at the end of life and the provision of spiritual end-of-life care was studied. The survey included questions about their last patient who died and the provided spiritual care. Physicians' perception of spirituality was measured with 15 items obtained from a systematic review of instruments that measure spirituality at the end of life. Fifteen additional non-spiritual items concerned psychosocial needs (10) and other issues (5).

48.4% of the respondents reported they provided spiritual end-of-life care to the last resident they cared for. 51.8% of the physicians identified all 15 spiritual items. 95.4% included one or more psychosocial items in their perception of spirituality, 49.1% included at least one item on other issues. Most physicians included non-spiritual issues in their perception of spiritual end-of-life care. Those physicians with a broader perception of spirituality at

the end-of-life, reported more often that they provided spiritual end-of-life care. Also, more religiousness and additional training in palliative care was associated with reported provision of spiritual care by physicians. Further research is recommended on the concept of spirituality at the end of life. Additional training of elderly care physicians in reflecting their own perception of spirituality, distinguishing spiritual needs from psychosocial and other needs at the end of life, and training in multidisciplinary spiritual end of life care may contribute to quality of end-of-life care to nursing home residents.

Interpretation and discussion of the results

The model with the dimensions of spirituality at the end of life and their associations may contribute to theoretical comprehension of the concept. The dimension spiritual coping appears to be understudied. Further exploration of this dimension may be important to understand how people at the end of life may cope with spiritual distress.

The key findings of the survey have shown that physicians have difficulties in delimiting the dimension of spirituality at the end of life from the other dimensions of end of life care. The inter-relationship between the three dimensions of end of life care: the spiritual, psychosocial and physical dimension in end-of-life care is very complex and further study is needed to attain a better understanding of this inter-relationships.

This thesis also shows that many physicians considered it difficult to address spiritual issues. In the survey many physicians stated they did not address spiritual issues. Two recent studies from the US and from Flanders, Belgium, reported that patients consider it important that their physicians ask about their spiritual coping and support mechanisms, and indicated that discussions between physicians and patients on spiritual issues may even lead to more appropriate medical advice and even lead to a change in medical decision and advance care planning. How might elderly care physicians be trained in exploring spiritual needs and/or spiritual resources in nursing home residents at the end of life? The US Consensus Conference report on improving the quality of spiritual care had recommended 'taking a spiritual history', including the assessment of patient's beliefs and values, their spiritual strengths and spiritual distress. Available screening instruments that may be helpful in such a training are the FICA instrument which is the most frequently used screening instrument, but also the 5 questions from the 'ars moriendi' model (the 'art of dying' model), that was introduced in the Dutch guideline Spiritual Care in Palliative Care. As spirituality at the end of life is a culturally sensitive concept, further study is needed to examine if one of the instruments/model is more suitable for Dutch physicians.

Physicians in our studies reported significantly more often that they provided spiritual care to residents with dementia, if their families had told them that faith or spirituality had been very important to the resident. Also, families' reports of satisfaction with the physicians' communication was a significant independent predictor for the provision of spiritual care. In the Dutch guideline on spiritual care in palliative care one of the conditions for the provision of spiritual care is the physicians' attention for the spiritual needs of the resident, by listening, supporting, recognizing and screening of spiritual needs. These are of course communication skills. Specific training in communication skills to discuss spiritual issues at the end of life, also with residents with dementia and their loved ones, may therefore be considered.

The results of the ethnographic study raise questions about if and how the lack of communication between the various disciplines on spiritual end-of-life issues of the nursing home resident, as well as the informal and formal care processes, affect spiritual wellbeing of these nursing home residents. However, the Dutch guideline of spiritual care in palliative care promotes a multidisciplinary approach, in which the various disciplines each have their own expertise, role and task, the health care chaplain being the trained professional in spiritual care. Further study will be needed to explore if and how a multidisciplinary approach is suitable for the Dutch situation, in which the health care chaplain is part of the team and the spiritual issues are part of the residents' care plan, and if and how this approach would be beneficial towards the spiritual caregiving at the end of life in nursing home residents.

Practice and policy recommendations

The results of the different studies in this thesis provide several components for spiritual interventions, that may contribute to the practice of spiritual caregiving, and consequently to spiritual wellbeing and quality of life of the nursing residents. These components include: attention for spiritual beliefs, especially if these beliefs have been very important to the nursing home resident, and attention for spiritual relationships, including the spiritual relationships that existed before the residents' admission in the nursing home. Also, spiritual activities may contain core components for spiritual intervention, such as praying, attending mass, singing hymns and (personal) spiritual rituals, as well as attention for peacefulness at the end of life, connectedness with loved ones, the completion of life with attention for unfinished business, acceptance of death, a sense of fulfilment in life, and finally, support for spiritual coping may be a core component for spiritual interventions.

Although the conditions for multidisciplinary collaboration in Dutch nursing homes are often favourable, with on staff physicians, psychologists, therapists and often also on staff spiritual counsellors, our findings indicate that multidisciplinary collaboration is still challenging, including collaboration with spiritual counsellors. The Dutch multidisciplinary guideline on spiritual care in palliative care thus appears to be ahead of time. Nevertheless, the first best practices on palliative care in dementia have now been published the Netherlands, which may be inspirational for further development of multidisciplinary palliative care in Dutch nursing homes, including spiritual care.

With regard to bridging the communication challenges between the different disciplines with their own subcultures and 'languages', it might be worthwhile for all the members in the multidisciplinary team to realize that each discipline might have valuable information, and that actively inquiring after this information and acknowledging the importance of this information could lead to improved support of nursing home residents and their loved ones at the end of life.

Several studies in this thesis show that physicians do not always assess spiritual needs and do not always provide spiritual care to their residents. However, a recent Belgian study confirmed that patients do not only want their physicians to ask about their spiritual needs, but also shows that this information may be important in discussing advance care planning. Additional training in addressing spiritual issues at the end of life may support elderly care physicians in their communication skills on spiritual issues at the end of life.

Recommendations for future research

As stated above, the results of the different studies in this thesis provide components for spiritual interventions. To determine which of these components may be considered as core components for spiritual interventions, a Delphi study with experts from different professional disciplines (spiritual counsellors, nurses, physicians, psychologists, researchers, nursing home residents) may be performed to prioritize the different components of spiritual interventions.

Another important topic of further research would be the collaboration and communication within the multidisciplinary team on spirituality and spiritual issues of the nursing home residents. It is yet unclear whether a lack of communication between the health care chaplain and the rest of the multidisciplinary team is a hindrance to spiritual care giving, even though the Dutch guideline for Spiritual Care in Palliative Care promotes collaboration with the health care chaplain, as being the expert on spiritual caregiving. Possibly there are settings in the Netherlands that have multidisciplinary teams who collaborate extensively with (their) health care chaplains, thereby providing an opportunity to study if and how this collaboration could improve spiritual caregiving to nursing home residents. An ethnographic study would be a suitable research method to explore this topic further.

In our focus group study, physicians stated that they did not feel competent to discuss spiritual issues with nursing home residents and their loved ones at the end of life. According to the Dutch Guideline Spiritual Care in Palliative Care however, physicians are expected to assess residents' spiritual resources and spiritual needs, and to refer to a spiritual counsellor when this may be beneficial to the resident. Therefore, supporting physicians' skills in addressing spiritual issues may be a practical way to improve spiritual caregiving at the end of life. To explore if additional training for physicians is beneficial to spiritual support for nursing home residents, a pilot study during the vocational training of elderly care physicians may be performed, using items from the FICA instrument and/or questions from the 'ars moriendi' model in natural conversations with nursing home residents and/or their relatives- and addressing spiritual needs.

We developed a model on spirituality at the end of life, based on empirical research. Further research on the model of spirituality at the end of life with its three dimensions is needed, and a validation study in one or more countries of the model on spirituality may be supportive to the understanding of this complex and cultural sensitive concept.

Future research may also be important on the relationship between the spiritual dimension and the psychosocial and physical dimension of palliative care, as spirituality is still the least studied dimension of palliative care. A Delphi study with experts from different professional disciplines (spiritual counsellors, physicians, psychologists, psychiatrists and researchers) may be performed to contribute to understanding of the distinction between spiritual dimension and the other dimensions of palliative care. This may lead not only to a better understanding of the spiritual dimension and subsequently better assessment of spiritual needs, but ultimately to better provision of spiritual care at the end of life, including care for nursing home residents.

Samenvatting

Recent onderzoek dat in 21 landen werd uitgevoerd liet zien dat bijna een vijfde van alle sterfgevallen van ouderen in het verpleeghuis plaatsvindt. In het Verenigd Koninkrijk, België en Nederland betreft het zelfs een kwart van alle sterfgevallen. Het zorglandschap in Nederland is sterk aan het veranderen, ook met betrekking tot zorg rond het levenseinde, waarbij het onder andere de intentie is dat mensen langer thuis kunnen blijven wonen. Toch zal het verpleeghuis voor veel mensen de plek zijn waar zij zorg rond het levenseinde zullen ontvangen en uiteindelijk zullen sterven. Voor deze mensen is het heel belangrijk dat zij goede zorg krijgen aan het einde van hun leven, inclusief spirituele zorg.

Palliatieve zorg is geworteld in en ontwikkeld vanuit het werk van Dame Cicely Saunders. De huidige door de Wereld Gezondheidsorganisatie geformuleerde definitie van palliatieve zorg dateert uit 2002 en luidt: "Palliatieve zorg is een benadering die de kwaliteit van het leven verbetert van patiënten en hun naasten die te maken hebben met een levensbedreigende aandoening, door het voorkomen en verlichten van lijden, door middel van vroegtijdige signalering en zorgvuldige beoordeling en behandeling van pijn en andere problemen van lichamelijke, psychosociale en spirituele aard." Alhoewel de spirituele dimensie dus al meer dan tien jaar een van de dimensies van palliatieve zorg is, is het nog steeds de minst ontwikkelde dimensie. Spirituele zorg staat de laatste decennia wel meer in de belangstelling. Dit heeft geleid tot het includeren van spirituele zorg als een dimensie van palliatieve zorg, daarnaast is er ook een toenemend aantal onderzoeken gedaan naar spiritualiteit en spirituele zorgverlening rond het levenseinde.

Het is erg moeilijk om een goede definitie van 'spiritualiteit' te geven. Dit heeft tot gevolg dat 'spiritualiteit' op verschillende manieren wordt geïnterpreteerd. In 2009 was er in de Verenigde Staten een Consensus Conferentie met als thema het verbeteren van de kwaliteit van spirituele zorg als een dimensie van palliatieve zorg. Experts uit verschillende

disciplines (artsen, verpleegkundigen, geestelijk verzorgers en onderzoekers) kwamen toen tot de volgende definitie van spiritualiteit: “Spiritualiteit is het aspect van het mens-zijn dat refereert aan de manier waarop individuen betekenis en zin geven aan de manier waarop zij hun verbondenheid met henzelf, anderen, de natuur en met het belangrijke of heilige ervaren.”

In Nederland bevat het boek “Palliatieve Zorg: Richtlijnen voor de praktijk” ook een richtlijn over Spirituele zorg. Spiritualiteit wordt daarin als volgt omschreven: “Spiritualiteit is het levensbeschouwelijk functioneren van de mens, waartoe ook de vragen van zinervaring en zingeving gerekend worden’. Het gaat bij spiritualiteit om alle mogelijke - van godsdienstige tot alledaagse - bronnen van inspiratie. Voor sommige mensen ligt het accent hierbij op het gevoelsleven (bijv. bidden, genieten van de natuur, literatuur, muziek, kunst) of activiteiten (mediteren, rituelen voltrekken of zich inzetten voor een goede zaak), anderen beleven het meer intellectueel (contemplatie, studie). Spiritualiteit heeft invloed op het hele bestaan, is dynamisch, en heeft meer te maken met de bron van een levenshouding dan met een af te bakenen levensgebied”.

De medische zorg in Nederlandse verpleeghuizen wordt voornamelijk door specialisten ouderengeneeskunde verleend. Naast de directe medische zorg is de specialist ouderengeneeskunde ook verantwoordelijk voor de inhoud van het zorgleefplan van de bewoner, waarin alle zorgvragen moeten worden opgenomen, inclusief spirituele vragen. Tevens moet duidelijk zijn op welke wijze en door wie aan deze behoeften tegemoet wordt gekomen.

Veel studies naar de rol van de arts met betrekking tot spirituele zorg komen uit Noord-Amerika. Artsen lijken relatief onbekend te zijn met het herkennen van en aandacht besteden aan vragen over spiritualiteit, ondanks het feit dat patiënten deze vragen hebben. En hoewel het belang van spirituele zorg door artsen steeds meer herkend wordt in de laatste decennia, inclusief spirituele zorg aan het einde van het leven, stellen de meeste artsen echter pas vragen aan hun patiënten over religie of spiritualiteit als de patiënt stervende is. Vaak worden gebrek aan tijd en aan scholing genoemd als belemmeringen. Spirituele problemen worden vaak niet herkend en het wordt vaak niet gezien als de verantwoordelijkheid van de arts om aandacht te besteden aan spirituele behoeften. Het is onduidelijk of de resultaten van deze studies uit Noord Amerika kunnen worden geëxtrapoleerd naar de Nederlandse situatie, omdat de Verenigde Staten een religieus land is waar de meerderheid van de inwoners lid zijn van een kerkgenootschap, terwijl Nederland een typisch West-Europees, geseculariseerd land is.

Zou spiritualiteit aan het leven ook belangrijk kunnen zijn voor mensen met dementie? Een belangrijke vraag, aangezien een kwart van de mensen van 85 jaar en ouder sterft met dementie, terwijl ongeveer de helft van alle verpleeghuisbewoners dementie heeft. Spiritualiteit bij mensen met dementie is nog steeds een nauwelijks onderzocht onderwerp. Het is onduidelijk of en hoe Nederlandse verpleeghuisbewoners met dementie spirituele levensinzichten ontvangen, en of er bevorderende factoren kunnen worden vastgesteld met betrekking tot spirituele levensinzichten voor verpleeghuisbewoners met dementie.

Dit proefschrift wil een bijdrage leveren aan een beter begrip van het concept ‘spiritualiteit aan het einde van het leven’. Ook onderzoekt het de opvattingen van specialisten ouderengeneeskunde over spiritualiteit aan het einde van het leven en over hun rol bij spirituele levensinzichten in het verpleeghuis. Daarnaast wordt de spirituele levensinzichten in Nederlandse verpleeghuizen onderzocht en wordt geprobeerd factoren vast te stellen die spirituele levensinzichten voor verpleeghuisbewoners met dementie bevorderen.

De onderzoeksvragen van dit proefschrift zijn de volgende:

1. Wat verstaan wij onder spiritualiteit aan het einde van het leven?
2. Wat zijn de opvattingen van specialisten ouderengeneeskunde over spiritualiteit aan het einde van het leven en over hun rol bij de spirituele levensinzichten in het verpleeghuis?
3. Welke spirituele levensinzichten worden verleend aan Nederlandse verpleeghuisbewoners, waaronder aan bewoners met dementie?
4. Welke bevorderende factoren kunnen worden vastgesteld met betrekking tot spirituele levensinzichten voor verpleeghuisbewoners met dementie.

‘Mixed Method’ onderzoeksdesign

Omdat de onderzoeksvragen verschillend van aard zijn, is er voor een ‘mixed method’ onderzoeksdesign gekozen, waarbij verschillende kwalitatieve en kwantitatieve onderzoeksmethoden zijn gebruikt.

1. Om de eerste vraag te beantwoorden, werd er een **systematisch literatuuronderzoek** gedaan naar ‘spiritualiteit rond het levenseinde’. Een systematisch literatuuronderzoek geeft een overzicht van de informatie over ‘spiritualiteit aan het einde van het leven’ door het opzoeken, beoordelen, en samenvoegen van de evidence uit afzonderlijke studies die relevant zijn voor het beantwoorden van de onderzoeksvraag, en is verricht volgens een transparante en reproduceerbare methode.
2. Om de tweede vraag te beantwoorden, werd onder specialisten ouderengeneeskunde een focusgroep onderzoek gehouden naar hun opvattingen over spiritualiteit aan het einde van het leven en over hun rol bij spirituele levensinzichten in het verpleeghuis. Deze kwalitatieve onderzoeksmethode is zeer geschikt voor het bestuderen en verhelderen van onderwerpen door middel van interactie tussen de deelnemers. Om te onderzoeken of deze resultaten ook gegeneraliseerd konden worden hebben we ook items over deze onderwerpen opgenomen in een landelijk **vragenlijst onderzoek** onder een representatieve steekproef van specialisten ouderengeneeskunde.
3. Om de derde vraag te beantwoorden, werd een **participerend observatieonderzoek** uitgevoerd naar spirituele levensinzichten binnen de dagelijkse verpleeghuiszorg op twee verpleegafdelingen in een Nederlandse verpleeghuis: een afdeling voor bewoners met dementie en een afdeling voor bewoners met fysieke beperkingen. Een participerend observatie onderzoek geeft de mogelijkheid om toegang te krijgen tot gedrag en interacties van deelnemers, ook waar zij zich niet bewust van zijn. Dit levert rijke holistische inzichten op ten aanzien van opvattingen en handelingen van de deelnemers.
4. Om de vierde vraag te beantwoorden, werden de data van twee kwantitatieve onderzoeken geanalyseerd. Het eerste onderzoek is een **retrospectieve studie**, waarin levensinzichten voor verpleeghuisbewoners met dementie (inclusief de spirituele aspecten) in antroposofische en reguliere verpleeghuizen werd vergeleken met behulp van de “End Of Life in Dementia scales”. In het tweede onderzoek zijn de data gebruikt van het **prospectieve “Zorg bij Dementie” onderzoek**, waarbij onafhankelijke predictoren

voor het verlenen van spirituele levenseindezorg voor mensen met dementie werden vastgesteld.

Hoofdstuk 2 beschrijft de resultaten van een **systematisch literatuuronderzoek** naar 'Spiritualiteit aan het einde van het leven'. In dit onderzoek werd spiritualiteit aan het einde van het leven geconceptualiseerd door dimensies van spiritualiteit rond het levenseinde vast te stellen, gebaseerd op een analyse van items in meetinstrumenten die spiritualiteit in levenseinde-populaties meten. In de 36 artikelen die voldeden aan de inclusiecriteria, werden 24 instrumenten gevonden. Daarvan hadden negen instrumenten adequate inhoudsvaliditeit. Alle items van deze negen instrumenten werden gebruikt om dimensies van spiritualiteit te identificeren. Om de items van de instrumenten zo zorgvuldig mogelijk te representeren, werd een model van spiritualiteit aan het levenseinde samengesteld. Het model maakt onderscheid tussen de volgende drie dimensies: Spiritueel Welbevinden (bijv. innerlijke vrede, vertrouwen, hoop, acceptatie, zingeving, betekenis, verbondenheid, voldoening, comfort), Spirituele Cognitieve en Gedrags-Context (Spirituele Levensovertuiging, Spirituele Activiteiten en Spirituele Relaties), en Spirituele Coping. Het model laat ook de relaties tussen de drie dimensies zien. De dimensie Spiritueel Welbevinden wordt beschouwd als uitkomst, waar Spirituele Coping evenals de Spirituele Cognitieve en Gedrags-Context toe kunnen bijdragen. Dit model kan onderzoekers ondersteunen bij het plannen van onderzoek en het kiezen van geschikte uitkomstmaten, en zou zorgverleners kunnen ondersteunen bij het plannen van spirituele zorg.

In **Hoofdstuk 3** worden de resultaten gepresenteerd van het **focusgroep onderzoek** met Nederlandse specialisten ouderengeneeskunde, die werkzaam zijn in het verpleeghuis. Hierin hebben we onderzoek gedaan naar de opvattingen van Nederlandse specialisten ouderengeneeskunde over spiritualiteit en spirituele levenseindezorg in het verpleeghuis. Er werden drie focusgroepen georganiseerd, elk met 6 deelnemers. Om te zorgen voor voldoende variatie in opvattingen en meningen, zorgden we voor zes tot acht deelnemers per focusgroep, waarbij specialisten ouderengeneeskunde met verschillende religieuze achtergronden, professionele interesse en ervaring werden geselecteerd. De discussies richtten zich op de volgende onderwerpen: (1) spiritualiteit en spiritueel welbevinden aan het einde van het leven, (2) de rol van de specialist ouderengeneeskunde bij het verlenen van spirituele levenseindezorg aan bewoners met fysieke beperkingen en bewoners met dementie, en (3) belemmerende en bevorderende factoren bij het verlenen van spirituele levenseindezorg. Deelnemers beschouwden spiritualiteit in eerste instantie als religie, maar na verdere reflectie werden ook andere aspecten genoemd, die in de literatuur worden gedefinieerd als spiritueel welbevinden, zoals: vrede hebben met de situatie, harmonie, vertrouwen in een leven na de dood, afronden van het leven en zingeving. Sommige deelnemers voelden zich niet direct verantwoordelijk voor het verlenen van spirituele zorg, waarbij gebrek aan expertise en tijd werden genoemd als belemmerende factoren. Communicatie met geestelijk verzorgers werd over het algemeen ingewikkeld gevonden. Wat betreft het signaleren van spirituele behoeften van en het verlenen van spirituele zorg aan bewoners met dementie werd de bemoeilijkte verbale communicatie gezien als een belemmerende factor. Deelnemers beschreven hoe religieuze voorwerpen daarbij konden helpen en hoe religieuze rituelen de bewoners ondersteunden in hun spirituele welbevinden. Daarom zou het vragen aan de bewoners naar de betekenis van hun geloof en kerkgenootschap belangrijke informatie op kunnen leveren en kunnen helpen om een gesprek over spiritualiteit te beginnen en passende spirituele zorg te verlenen. Er zouden scholingsprogramma's ontwikkeld kunnen worden om specialisten ouderengeneeskunde te ondersteunen in het aandacht geven

aan spirituele thema's. Spirituele rituelen en voorwerpen, evenals 'spirituele reminiscentie' zouden verpleeghuisbewoners met dementie kunnen helpen met het beleven van hun spiritualiteit.

Hoofdstuk 4 beschrijft het **participerend observatie onderzoek** in een Nederlands verpleeghuis, waarin onderzoek werd gedaan naar spirituele levenseindezorg aan verpleeghuisbewoners met fysieke beperkingen en met dementie, evenals de communicatie en samenwerking rond spirituele levenseindezorg tussen de verschillende disciplines, met een nadruk op de rol van de specialist ouderengeneeskunde. De studie werd uitgevoerd op een psychogeriatrische afdeling (waar overwegend voor bewoners met dementie woonden) en een somatische afdeling met bewoners die fysieke beperkingen hadden. De resultaten lieten zien dat artsen niet actief aandacht besteden aan spirituele problemen. Het was ook geen onderdeel van formele werkzaamheden van het zorgpersoneel. We zagen geen communicatie tussen de artsen en de geestelijk verzorger. Echter, vlak voordat een bewoner overleed, startten de verzorgenden een zorgproces dat gericht was op het (spirituele) welbevinden, waarbij zij de bewoner knuffelden, en aandacht hadden voor het afronden van het leven van de bewoner met hun dierbaren, voor rituelen en muziek. Dit werd overigens niet vermeld in het zorgleefplan of het medisch dossier. De verzorgenden ondersteunden de bewoners hierin zelfs buiten het werk om in hun vrije tijd. Daarnaast leken er professionele subculturen te bestaan, bijvoorbeeld die van verpleegkundigen en artsen, waarin aan het gedrag van de bewoners een verschillende betekenis werd gegeven, afhankelijk van het referentiekader binnen betreffende subcultuur. De resultaten van dit onderzoek roepen vragen op over het gebrek aan communicatie over spirituele levenseindezorg tussen de verschillende disciplines, en hoe de informele en formele zorgprocessen het spiritueel welbevinden van verpleeghuisbewoners aan het einde van het leven beïnvloeden.

Hoofdstuk 5 bespreekt de resultaten van een **retrospectief onderzoek**, waarin werd onderzocht of en hoe de levensbeschouwelijke achtergrond van een verpleeghuis invloed heeft op de kwaliteit van leven en tevredenheid met de zorg aan verpleeghuisbewoners met dementie. We vergeleken levenseindezorg (inclusief spirituele aspecten) in twee antroposofische en twee reguliere verpleeghuizen voor bewoners met dementie, met behulp van de "End-of-Life in Dementia" vragenlijst (EOLD). Zes weken nadat een verpleeghuisbewoner op een psychogeriatrische afdeling was overleden, ontving de vertegenwoordiger van de bewoner (te contactpersoon) een brief van de onderzoeker met het verzoek om deel te nemen aan dit onderzoek. Wanneer die toestemde, werd de EOLD vragenlijst, waaraan verschillende vragen waren toegevoegd over kenmerken van de bewoner en de respondent, naar de desbetreffende respondent gestuurd. 60 contactpersonen van overleden bewoners werden benaderd, van wie 34 deelnamen aan het onderzoek (57%). De resultaten lieten zien dat er geen verschil was in de gemiddelde scores op de 'Satisfaction With Care' [tevredenheid met zorg]-schaal tussen beide typen verpleeghuizen. Het antroposofische verpleeghuis had significant hogere scores op de 'Symptom Management' [symptoom management] en 'Comfort Assessment in Dying' [evaluatie van comfort bij overlijden] schalen evenals de sub-schaal welbevinden van de 'Comfort Assessment in Dying'-schaal. De sub-schaal welbevinden bestaat uit drie items die in de literatuur over spiritualiteit te vinden zijn (en in instrumenten die spiritualiteit meten) en die verwijzen naar spiritueel welbevinden: in het bijzonder sereniteit, maar ook vrede en rust. De resultaten lieten zien dat overlijden met dementie in antroposofische verpleeghuizen gunstiger verloopt. Er is nader prospectief onderzoek nodig naar de vraag hoe de levensbeschouwelijke oriëntatie van verpleeghuizen 'vertaald' wordt in het dagelijkse zorgproces, zoals besluitvorming in multidisciplinair overleg, familiegesprekken, en aanvullende niet-medicamenteuze behan-

delingen. Er is nader prospectief onderzoek nodig naar de vraag met welke onderdelen van het zorgproces dit samenhangt, zoals besluitvorming in multidisciplinair overleg, familiegesprekken en aanvullende niet-medicamenteuze behandelingen. Onze resultaten wijzen erop dat sterven met dementie in de antroposofische verpleeghuizen gunstiger verloopt. Er is nader prospectief onderzoek nodig naar de vraag met welke onderdelen van het zorgproces dit samenhangt, zoals besluitvorming in multidisciplinair overleg, familiegesprekken en aanvullende niet-medicamenteuze behandelingen. Er is nader prospectief onderzoek nodig naar de vraag met welke onderdelen van het zorgproces dit samenhangt, zoals besluitvorming in multidisciplinair overleg, familiegesprekken en aanvullende niet-medicamenteuze behandelingen. Er is nader prospectief onderzoek nodig naar de vraag met welke onderdelen van het zorgproces dit samenhangt, zoals besluitvorming in multidisciplinair overleg, familiegesprekken en aanvullende niet-medicamenteuze behandelingen.

In **Hoofdstuk 6** worden de resultaten van het **prospectieve** “Zorg bij Dementie” **onderzoek** gepresenteerd, waarin predictoren worden geïdentificeerd voor het verlenen van spirituele levenseindezorg aan verpleeghuisbewoners met dementie. Er werd gebruikt gemaakt van de data van het “Zorg bij Dementie” onderzoek (2007–2011), waarin prospectief gegevens werden verzameld in 28 instellingen voor langdurige zorg. De uitkomstmaat van de Generalized Estimating Equations regressie analyse was: in hoeverre spirituele zorg was verleend vlak voor het overlijden, zoals gerapporteerd door de specialist ouderengeneeskunde die verantwoordelijk was voor de levenseinde zorg (bijvoorbeeld laatste sacramenten, rituelen of andere spirituele zorg verleend door een geestelijk verzorger of door zorgpersoneel). Potentiele predictoren waren: indicatoren voor hoge kwaliteit van zorg, cliënt-gerichte zorg en palliatieve zorg, demografische gegevens en enkele andere, door de literatuur ondersteunde, factoren. Volgens de artsen werd er kort voor het overlijden spirituele levenseindezorg verleend aan 20.8% van de bewoners. Onafhankelijke predictoren van spirituele levenseindezorg waren: tevredenheid van familie met de communicatie van artsen aan het begin van de opname, en ook of levensbeschouwing of spiritualiteit erg belangrijk was voor de bewoner, (onafhankelijk of dit ook belangrijk was voor de arts). Verder was het hebben van een vrouwelijke mantelzorg een onafhankelijke predictor. De resultaten van dit onderzoek laten zien dat palliatieve zorgindicatoren niet voorspellend waren voor spirituele levenseindezorg; palliatieve zorg in dementie zou mogelijk beter gedefinieerd moet worden en beter geïmplementeerd moeten worden in de zorg. Communicatie tussen arts en familie bij opname van de bewoner kan belangrijk zijn om spirituele levenseindezorg te optimaliseren.

Hoofdstuk 7 beschrijft de resultaten van een cross-sectioneel **vragenlijst onderzoek** onder 642 specialisten ouderengeneeskunde, waarin gevraagd werd naar hun perceptie van spiritualiteit aan het einde van het leven en naar de spirituele zorg die zij aan de verpleeghuisbewoner verleenden aan het levenseinde. Tevens werd de relatie tussen hun perceptie van spiritualiteit rond het levenseinde en het verlenen van spirituele levenseinde zorg onderzocht. De vragenlijst bevatte onder andere vragen over hun meest recent overleden patiënt en de verleende spirituele zorg. De perceptie van spiritualiteit aan het einde van het leven werd gemeten met 15 items verkregen uit een systematisch literatuuronderzoek naar instrumenten die spiritualiteit rond het levenseinde meten. Vijftien niet-spirituele items werden toegevoegd, die betroffen psychosociale behoeften (10) en andere behoeften (5). 48.4% van de respondenten antwoordden dat zij spirituele levenseindezorg hadden verleend aan hun meest recent overleden patiënt. 51.8% van de artsen includeerden alle 15 spirituele items in hun perceptie van spiritualiteit. 95.4% includeerde een of meer psycho-

sociale items, 49.1% includeerde tenminste een item met betrekking tot andere behoeften. De meeste artsen includeerden niet-spirituele items in hun perceptie van spiritualiteit aan het einde van het leven. Artsen met een degelijke bredere opvatting van spiritualiteit aan het einde van het leven, berichtten vaker dat zij spirituele levenseindezorg verleenden. Ook sterkere religiositeit en het afronden van de kaderopleiding palliatieve zorg werd geassocieerd met het verlenen van spirituele zorg door artsen. Verder onderzoek naar het concept van spiritualiteit rond het levenseinde wordt aanbevolen. Extra scholing van specialisten ouderengeneeskunde, waarbij ze reflecteren op hun eigen opvatting van spiritualiteit, het leren spirituele behoeften van psychosociale en ander behoeften aan het levenseinde van elkaar te onderscheiden, en training in multidisciplinaire spirituele levenseindezorg zou kunnen bijdragen aan de kwaliteit van levenseinde zorg voor verpleeghuisbewoners.

Interpretatie en discussie van de resultaten

Het model van spiritualiteit aan het einde van het leven, met drie dimensies en hun onderlinge relaties, kan bijdragen aan het theoretisch begrip van het concept ‘spiritualiteit aan het einde van het leven’. Naar de dimensie Spirituele Coping is nog weinig onderzoek verricht, verder onderzoek naar deze dimensie kan belangrijk zijn om inzicht te krijgen in hoe mensen aan het einde van hun leven kunnen omgaan met spirituele nood.

De belangrijkste resultaten van het vragenlijst onderzoek laten zien dat de artsen moeite hebben om de spirituele dimensie onderscheiden van de andere dimensies van palliatieve zorg. De onderlinge relatie tussen deze drie dimensies van palliatieve zorg: de spirituele, psychosociale en fysieke dimensie is complex en verder onderzoek is nodig om een beter begrip te krijgen van deze onderlinge relaties.

Dit proefschrift laat ook zien dat veel artsen het moeilijk vinden om aandacht te geven aan vragen van verpleeghuisbewoners op spiritueel gebied. In het vragenlijst onderzoek gaven veel artsen aan dat zij geen aandacht besteedden aan spirituele vragen. Twee recente onderzoeken uit de Verenigde Staten en uit Vlaanderen, België, lieten echter zien dat patiënten het belangrijk vinden dat artsen hen vragen naar hun manier van ‘spirituele coping’ en naar hulpbronnen daarbij, en gaven daarbij aan dat een gesprek tussen arts en patiënt over spirituele vragen zelfs tot een passender medisch advies en zelfs tot verandering in medische besluitvorming en advance care planning kan leiden. Hoe zouden specialisten ouderengeneeskunde geschoold kunnen worden in het verkennen van spirituele behoeften van en/of spirituele (hulp)bronnen van verpleeghuisbewoners aan het einde van het leven? In het rapport van de Consensus Conference in de VS met betrekking tot het verbeteren van de kwaliteit van spirituele zorg als een dimensie van palliatieve zorg, wordt ‘het in kaart brengen van de situatie van de patiënt met betrekking tot spirituele zorg’ aanbevolen, waaronder de levensovertuiging en ‘waarden’ van de patiënt, spirituele bronnen van kracht, hoop, evenals de spirituele nood van de patiënt. Beschikbare screeningsinstrumenten die behulpzaam zouden kunnen zijn een dergelijke scholing zijn: het ‘FICA instrument’ (het meest gebruikte screeningsinstrument), maar ook de 5 vragen van het ‘ars moriendi’ model (‘kunst van het sterven’), dat is geïntroduceerd in de Nederlandse richtlijn Spirituele Zorg in Palliatieve Zorg. Omdat spiritualiteit rond het levenseinde een cultureel gevoelig concept is, is verder onderzoek nodig om na te gaan of een van de instrumenten/modellen meer geschikt zijn voor Nederlands artsen.

Artsen gaven significant vaker aan dat zij spirituele zorg aan bewoners met dementie hadden verleend, als hun familieleden hen verteld hadden dat religie of spiritualiteit erg

belangrijk was voor de bewoner. Ook was de tevredenheid van familie over de communicatie van arts een significante onafhankelijke predictor voor het verlenen van spirituele zorg. Een van de voorwaarden van de Nederlands richtlijn voor spirituele zorg in palliatieve zorg is dat de arts aandacht heeft voor de spirituele behoeften van de bewoner, door het luisteren naar en ondersteunen, herkennen en screenen van spirituele behoeften. Dit zijn uiteraard communicatievaardigheden. Specifieke scholing in communicatievaardigheden om spirituele zaken rond het levenseinde te bespreken zou daarom overwogen kunnen worden, ook bij bewoners met dementie en hun dierbaren.

De resultaten van het participierend observatie onderzoek roepen vragen op over multidisciplinaire samenwerking, en hoe een gebrek aan communicatie met betrekking tot spirituele zaken aan het einde van het leven tussen de verschillende disciplines van invloed kan zijn op het spiritueel welbevinden van de verpleeghuisbewoner, evenals de invloed van informele en formele zorgprocessen hierop. In de Nederlandse richtlijn 'Spirituele zorg in Palliatieve Zorg' wordt een multidisciplinaire benadering aanbevolen, waarin de verschillende disciplines elk hun eigen expertise, rol en taak hebben, met de geestelijk verzorger als professional die specifiek is opgeleid in het verlenen van spirituele zorg. Verder onderzoek is nodig om te verkennen of en hoe een multidisciplinaire aanpak geschikt is binnen het Nederlandse zorgsysteem, waarin de geestelijk verzorger deel uitmaakt van het team en spirituele vragen opgenomen worden in het zorg-leefplan van de bewoners, en of en hoe deze benadering gunstig zou zijn ten aanzien van het verlenen van spirituele zorg aan het einde van het leven aan verpleeghuisbewoners.

Aanbevelingen voor praktijk en beleid

De resultaten van de studies in dit proefschrift leveren verschillende componenten voor spirituele interventies op, die kunnen bijdragen aan het verlenen van spirituele zorg, en daarmee bijdragen aan spiritueel het spiritueel welbevinden en de kwaliteit van leven van verpleeghuisbewoners. Deze componenten zijn onder andere: aandacht voor de levensbeschouwing van de verpleeghuisbewoner, zeker als deze altijd erg belangrijk zijn geweest voor de bewoner, en aandacht voor spirituele relaties, waaronder spirituele relaties die al bestonden voordat de bewoner werd opgenomen in het verpleeghuis. Ook kunnen spirituele activiteiten belangrijke componenten bevatten voor spirituele interventie, zoals bidden, de mis bijwonen, het zingen van religieuze liederen en (persoonlijke) spirituele rituelen, evenals aandacht voor innerlijke rust en vrede rond het levenseinde, je verbonden voelen met dierbaren, het afronden van het leven met aandacht voor onafgemaakte zaken, acceptatie van de dood, een gevoel van vervulling in je leven en, tot slot het ondersteunen bij spirituele coping kan een belangrijke component zijn voor spirituele interventies.

Alhoewel de voorwaarden voor multidisciplinaire samenwerking in Nederlandse verpleeghuizen gunstig zijn, met vaste artsen, psychologen, therapeuten en vaak ook geestelijk verzorgers, laat dit proefschrift zien dat laat zien dat multidisciplinaire samenwerking nog steeds een uitdaging is. De Nederlandse multidisciplinaire richtlijn voor spirituele zorg in palliatieve zorg lijkt dus nog op de werkelijkheid vooruit te lopen. De eerste best practices van palliatieve zorg in dementie zijn nu gepubliceerd in Nederland, die kunnen inspirerend zijn voor de verdere ontwikkeling van multidisciplinaire palliatieve zorg in Nederlandse verpleeghuizen, waaronder spirituele zorg.

Een volgende aanbeveling betreft de uitdagingen op het gebied van communicatie tussen de verschillende disciplines met hun eigen subcultuur en taal. Het kan een goede

investering zijn voor alle leden van het multidisciplinaire team om zich te realiseren dat andere disciplines waardevolle informatie zouden kunnen hebben. Door het actief informeren naar deze informatie en het erkennen van het belang van deze informatie zou een betere ondersteuning van de verpleeghuisbewoner en hun dierbaren rond het levenseinde gerealiseerd kunnen worden.

Verschillende studies in dit proefschrift laten zien dat specialisten ouderengeneeskunde niet altijd aandacht besteden aan spirituele behoeften en/of spirituele zorg verlenen aan hun bewoners aan het einde van het leven. Een Belgisch onderzoek liet echter niet alleen zien dat patiënten willen dat artsen hen naar hun spirituele behoeften vragen, maar dat deze informatie ook belangrijk zou kunnen zijn in het bespreken van medisch beleid en advance care planning. Daarom kan scholing in het aandacht geven aan (communicatie vaardigheden met betrekking tot) spirituele zaken aan het einde van het leven, specialisten ouderengeneeskunde ondersteunen bij de communicatie hierover.

Aanbevelingen voor verder onderzoek

Zoals hierboven al aangegeven, leveren de resultaten van de verschillende studies in dit proefschrift componenten voor spirituele interventies. Om een prioritering aan te brengen in de verschillende mogelijke componenten, kan een Delphi-studie worden uitgevoerd onder experts met verschillende professionele achtergronden (geestelijk verzorgers, artsen, psychologen, psychiaters en onderzoekers).

Een volgend belangrijk thema voor verder onderzoek is de samenwerking en communicatie in het multidisciplinaire team waar het spiritualiteit en spirituele problemen van verpleeghuisbewoners betreft. Het is tot op heden onduidelijk of moeizame communicatie tussen de geestelijk verzorger en de rest van het multidisciplinaire team een belemmerende factor is bij het verlenen van spirituele levenseindezorg, alhoewel de Nederlandse richtlijn voor Spirituele Zorg in Palliatieve Zorg een actieve samenwerking in een multidisciplinair team promoot, met de geestelijk verzorger als de expert op het gebied van spirituele zorgverlening. Mogelijk zijn er zorginstellingen in Nederland met dergelijke multidisciplinaire teams, die de mogelijkheid zouden kunnen bieden om te onderzoeken of en hoe deze samenwerking spirituele zorgverlening aan verpleeghuisbewoners bevordert. Een participierend observatie onderzoek zou een geschikte methode zijn om dit thema verder te verkennen.

In het focusgroep-onderzoek, vertelden artsen dat zij zich niet competent voelden om spirituele zaken aan het levenseinde te bespreken met verpleeghuisbewoners en hun dierbaren. In de Nederlandse Richtlijn Spirituele Zorg in Palliatieve Zorg wordt echter beschreven dat van de arts wordt verwacht dat zij de spirituele krachtbronnen evenals spirituele behoefte van bewoners in kaart kunnen brengen, en weten hoe ze kunnen verwijzen naar een geestelijk verzorger, als dit de bewoner ten goede kan komen. Daarom kan het ondersteunen van de artsen ten aanzien van hun vaardigheden om spirituele zaken te bespreken, een praktische manier zijn om de spirituele levenseindezorg te verbeteren. Om te onderzoeken of extra scholing aan artsen hierbij kan helpen, zou een pilot studie uitgevoerd kunnen worden tijdens de specialisatie tot specialist ouderengeneeskunde, waarin een deel van de artsen de gebruikelijke opleiding krijgt en een ander deel de extra scholing krijgt in het in kaart brengen van spirituele zaken. Hierbij kan gebruik worden gemaakt van het FICA instrument of het 'ars moriendi' model binnen een normaal, ongeunsteld gesprek met verpleeghuisbewoners en/of hun geliefden, en zo aandacht besteden aan spiritualiteit

en spirituele behoeften. Ook kan onderzocht worden of een dergelijke scholing betere spirituele zorg oplevert.

We hebben een model ontwikkeld betreffende spiritualiteit aan het einde van het leven, gebaseerd op empirisch onderzoek. Verder onderzoek naar het model van spiritualiteit aan het einde van het leven met zijn drie dimensies is nodig, en een validatie-studie in een of meerdere landen van dit model zou het begrip van dit complexe en cultureel gevoelige onderwerp kunnen ondersteunen.

Daarnaast zal ook nader onderzoek van belang zijn naar de relatie tussen de spirituele dimensie en de psychosociale en fysieke dimensies van palliatieve zorg. Een Delphi-studie onder experts met verschillende professionele achtergronden (geestelijk begeleiders, artsen, psychologen, psychiaters en onderzoekers) zou uitgevoerd kunnen worden om bij te dragen aan het begrip van het onderscheid tussen de spirituele dimensie en andere dimensies van palliatieve zorg, met als uiteindelijk doel te zorgen voor een zo goed mogelijke kwaliteit van leven aan het einde van het leven. Ook van verpleeghuisbewoners in Nederland.

Let us be grateful to people who make us happy;
they are the charming gardeners
who make our souls blossom.

Marcel Proust

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SISTERS OF MERCY

Oh, the Sisters of Mercy, they are not departed or gone
They were waiting for me when I thought, I just cannot go on
And they brought me their comfort and later they brought me this song
Yes I hope you run into them, you who've been traveling so long

Leonard Cohen

In: *the songs of Leonard Cohen*

About the author

Marie-José Gijsberts was born in Geldrop on April 28 1952. She received her secondary education at the Sint Joris College in Eindhoven. In 1969 she moved to Groningen, where she completed her MA in medicine in 1974. At the Academie voor Fysiotherapie she received her Bachelor Fysiotherapie in 1980. For many years she enjoyed her work as a physiotherapist in a hospital, nursing homes, and a health care center in Utrecht.

The VU University in Amsterdam gave her the opportunity to finish her medical study in 2000. She graduated summa cum laude in 2002. After a year training in Geriatric Medicine she started her vocational training as an elderly care physician in 2003 at the VU university in Amsterdam and received her practical training at the Sarphatihuis in Amsterdam. She completed her vocational training in 2005, and started her additional training in Palliative Medicine at the University of Amsterdam and the VU Medical Center in Amsterdam, which she completed in 2007.

Marie-José lives in Amsterdam. She is practicing as an elderly care physician, and works as a consultant for the Palliative Team Midden Nederland at the IKNL (Comprehensive Cancer Center the Netherlands).

She is co-chair of the research subgroup of the EAPC taskforce Spiritual Care in Palliative Care.

List of publications

- Gijsberts MJ, Echteld MA, van der Steen JT, Muller MT, Otten RH, Ribbe MW, Deliëns L. Spirituality at the end of life: conceptualization of measurable aspects-a systematic review. *J Palliat Med* 2011 Jul;14(7):852-63.
- Gijsberts MJ, van der Steen JT, Muller MT, Hertogh CM, Deliëns L. Spiritual end-of-life care in Dutch nursing homes: an ethnographic study. *J Am Med Dir Assoc* 2013 Sep;14(9):679-84.
- Gijsberts MJ, van der Steen JT, Muller MT, Deliëns L. Zorg aan het levenseinde bij bewoners met dementie in antroposofische en reguliere verpleeghuizen: een pilot studie. *Tijdschr Gerontol Geriatr* 2008 Dec;39(6):256-64.
- van der Steen JT, Gijsberts MJ, Hertogh CM, Deliëns L. Predictors of spiritual care provision for patients with dementia at the end of life as perceived by physicians: a prospective study. *BMC Palliat Care* 2014 Dec 19;13(1):61
- van der Steen JT, Gijsberts MJ, Knol DL, Deliëns L, Muller MT. Ratings of symptoms and comfort in dementia patients at the end of life: comparison of nurses and families. *Palliat Med* 2009 Jun;23(4):317-24.
- van der Steen JT, Gijsberts MJ, Muller MT, Deliëns L, Volicer L. Evaluations of end of life with dementia by families in Dutch and U.S. nursing homes. *Int Psychogeriatr* 2009 Apr;21(2):321-9.
- van der Steen JT, van Soest-Poortvliet MC, Gijsberts MJ, Onwuteaka-Philipsen BD, Achterberg WP, Ribbe MW, Deliëns L, de Vet HC. Betere zorg rond levenseinde van patiënten met dementie: Trend naar tevredener familie en meer comfort van de stervende. *Ned Tijdschr Geneesk* 2013;157(17):A5324.
- Defining spirituality at the end of life. van der Steen JT, Gijsberts MJ, Echteld MA, Muller MT, Ribbe MW, Deliëns L. *J Palliat Med* 2009 Aug;12(8):677.
- van der Geer J, Gijsberts MJHE, Jansen-Segers MJ. Spirituele zorg. In: De Hosson SM, De Graeff, Netters F.J.S, Verhagen CAHHVM. *Probleemgeoriënteerd denken in de palliatieve zorg*. Utrecht, de Tijdstroom; 2011. P 333-342.
- Gijsberts MJ: Spirituality and spiritual palliative care in older people. In: Van den Block L, Albers G, Martins Pereira S, Onwuteaka-Philipsen B, Pasman R, and Deliëns L. *Palliative care for older people, A public health perspective*. Oxford, Oxford University Press; 2015
- Gijsberts MJ. Kwalitatief onderzoek: ook voor de ouderengeneeskunde? *Tijdschrift voor Ouderengeneeskunde* 2013;(5): 239-241