

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.