

# Spiritual care in dementia nursing

*A qualitative, exploratory study*

Liv Skomakerstuen Ødbehr



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UNIVERSITY OF OSLO  
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Department of Nursing Science

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# Abstract

**Background:** Spiritual care is included in nurses' holistic care. Descriptions of spirituality in research highlight humans search for the sacred, experiences of self-transcendence and connectedness (to self, to others and to God/a deity), with the end-point being the human experience of meaning. Nurses report spiritual care as being difficult to carry out, and that they lack knowledge in relation to what a spiritual dimension to nursing means and implies, and how to practise spiritual care in real terms. For people with dementia spiritual care is in general explored very little in research, and research on spiritual care for people living in nursing homes who have dementia is particularly sparse.

**Aim:** The main purpose of this doctoral thesis is to explore how nurses (registered nurses [RNs]) and care workers (licensed practical nurses [LPNs], auxiliary nurses, health workers, assistant nurses) carry out spiritual care in nursing homes, by focusing on their experiences and perspectives of the spiritual needs of people with dementia. The aim in studies I, II, III and IV were:

- I. To synthesize research that investigated how patients and caregivers view spiritual care, come to understand the spiritual needs of people with dementia and how caregivers provide care congruent with peoples' needs.
- II. To investigate nurses' and care workers' experience of spiritual needs among residents with dementia in nursing homes.
- III. To investigate how nurses and care workers carry out spiritual care for people with dementia in nursing homes.
- IV. To investigate nurses' attitudes towards and accommodation of patients' expressions of religiosity and faith in dementia care in nursing homes.

**Methods and design:** This doctoral project was of a qualitative exploratory design informed by phenomenological and hermeneutic methodology. Study I comprised a meta-synthesis of eight qualitatively empirical primary studies based on the perspectives of patients and caregivers providers. Studies II, III and IV were based on eight focus-group interviews (4x2), conducted in four different nursing homes in eastern Norway. Both nurses and care workers participated in the empirical study; 16 were nurses and 15 were care workers. Just one man attended.

**Main findings:** In the meta-synthesis, the first level of synthesis revealed that spiritual care included caregivers helping patients with religious rituals to provide a sense of comfort; coming to know a person with dementia provides an opportunity to understand that person's meaning and purpose. Attending to basic needs provides an opportunity to appreciate others vulnerability and humanness in the lives of people with dementia (Study I). Nurses' experience of the spiritual needs of people in nursing homes who have dementia was described as the need for serenity and inner peace, the need for confirmation, and the need to express faith and beliefs (Study II). The nurses provided spiritual care by integrating spiritual care into general care, creating togetherness and providing meaningful activities for the patients (Study III). Nurses' attitudes towards and accommodation of patients' expressions of religiosity and faith were described as a movement between two extremes, such as embarrassment versus comfort, unknown religious practices versus known religious practices, and death versus life (Study IV).

**Conclusions:** The spiritual care of nurses was considered to be tacit, intuitive and altruistic, and a part of general care. The nurses' understanding of the meaning of spiritual care was to meet patients' spiritual need for calmness and serenity, self-transcendence, inner peace, well-being and connectedness in relation to self, other people and God/a deity. Such relationships promoted a patient's sense of belonging and togetherness. Nurses facilitated activities that promoted patients' experiences of significance and meaning in everyday life, but their understanding of the meaning of this care for people with dementia seemed to be blurred. Nurses emphasized taking care of patients' expressions of faith and beliefs, although they did not have a clear understanding of the significance of religiosity in patients' lives. Nurses shared their patients' religious beliefs and faith to a limited extent, which affected their practice of caring. Some nurses experienced challenges and personal barriers by feeling embarrassed, ashamed and alienated in relation to the religious practice in nursing homes. It seemed as if the nurses favoured general spiritual care through subjective knowledge, but had less focus on particular religious spiritual care. Furthermore, nurses felt that they lacked knowledge and expertise to provide spiritual care. It was not common to talk about or incorporate spiritual care into dementia care in nursing homes, because the culture was not open to discussion of spiritual and religious concerns.

# Sammendrag

**Bakgrunn:** Åndelig omsorg er en del av sykepleiernes helhetlig omsorg. Beskrivelser av åndelighet i forskning vektlegger menneskers målrettede søker etter mening, opplevelser av selv- -transcendens og samhørighet (til seg selv, andre og Gud/ guddom), eller noe som oppleves hellig. Åndelig omsorg i forskning fremhever betydningen av å ivareta menneskers åndelighet, viktige verdier i pasienters liv, og å legge til rette for at mennesker kan uttrykke sin religiøsitet og tro. Det er begrenset med forskning som omhandler åndelig omsorg i demensomsorgen generelt, og få studier har utforsket åndelig omsorg til personer med demens som bor i sykehjem spesielt. Sykepleiere opplever at åndelig omsorg er utfordrende og vanskelig og at de mangler kunnskap om hva den åndelige dimensjonen innebærer i sykepleiepraksis.

**Mål og hensikt:** Hovedmålet med dette doktorgradsprosjektet var å undersøke hvordan sykepleiernes (offentlig godkjente sykepleiere) og helsefagarbeidere (helsefagarbeidere/ omsorgsarbeidere/ hjelpepleiere) utfører åndelig omsorg i sykehjem, gjennom å fokusere på deres erfaringer av og perspektiv på åndelige behov hos personer med demens. Målet med studie I, II, III og IV var:

- I. Å syntetisere forskning som omhandler hvordan pasienter og helsepersonell/ omsorgspersoner betrakter åndelig omsorg, forstår åndelige behov hos personer med demens og hvordan helsepersonell /omsorgspersoner utøver åndelig omsorg i samsvar med personens behov.
- II. Å undersøke sykepleieres og helsefagarbeideres opplevelse av åndelige behov hos personer med demens i sykehjem.
- III. Å undersøke hvordan sykepleiere og helsefagarbeidere utøver åndelig omsorg til personer med demens i sykehjem.
- IV. Undersøke sykepleiernes holdninger og imøtekommelse av pasientenes uttrykk for religiøsitet og tro hos pasienter med demens i sykehjem.

**Design og metode:** Prosjektet har et kvalitativt utforskende design basert på fenomenologisk og hermeneutisk metodologi. Studie I er en meta- -syntese av åtte kvalitative empiriske primærstudier, basert på pasienters og helsepersonells perspektiv. Videre ble det gjennomført åtte fokusgruppeintervjuer (4 x 2) i fire forskjellige sykehjem i Øst-Norge

(Studie II, III og IV). Både sykepleiere og omsorgsarbeidere deltok i de empiriske studiene. Seksten av dem var sykepleiere og femten av dem var omsorgsarbeidere. Bare en mannlig pleier deltok.

**Hovedfunn:** Åndelig omsorg i forskning overfor personer med demens, viser at det er behov for å tilrettelegge for pasientenes utøvelse av religiøs praksis, styrke pasientenes opplevelse av seg selv, og hjelpe pasienten til å oppleve deltakelse og engasjement i hverdagen gjennom å verdsette hver enkelt pasient (Studie I). Sykepleieres erfaring av åndelige behov hos personer med demens i sykehjem ble beskrevet som, behovet for ro og indre fred, behovet for bekreftelse og behovet for å uttrykke tro og livssyn (Studie II). Sykepleierne praktiserte åndelig omsorg i form av å integrere åndelig omsorg i den generelle omsorgen, gjennom fellesskap med pasientene og videre gjennom å legge til rett for meningsfulle aktiviteter for pasientene (Studie III). Sykepleiernes holdninger og imøtekommelse av pasientenes uttrykk for religiøsitet og tro ble beskrevet i form av en bevegelse mellom to ytterpunkter. Dette ble formulert som forlegenhet vs. komfort, ukjent religiøs praksis vs. kjent religiøs praksis, og død vs. liv (Studie IV).

**Konklusjon:** Sykepleiernes utførelse av åndelig omsorg ble betraktet som taus, intuitiv og altruistisk og ble sett på som en del av den generelle omsorgen. Sykepleiernes forståelse av åndelig omsorg var å møte åndelige behov hos pasientene i form av ro, selv-transcendens, indre fred, velvære og kontakt i relasjonen til seg selv, til andre og til Gud. Slike relasjoner fremmet pasientens opplevelse av tilhørighet og samhold, og forhindret opplevelsen av ensomhet. Sykepleierne la til rette for aktiviteter som fremmet pasientens erfaring av mening i hverdagslivet, selv om sykepleiernes forståelse av pasientenes meningsdannelse var utydelig. Sykepleierne vektla å vise omsorg for pasientenes uttrykk for tro og livssyn men hadde en uklar forståelse av religiøsitetens betydning i pasientenes liv. Sykepleierne erfarte at de i liten grad delte pasientenes perspektiv på religiøsitet og tro, noe som påvirket deres omsorgs-praksis. Noen sykepleiere erfarte personlige barrierer og utfordringer i form av følelsen av forlegenhet, skam og fremmedgjøring i relasjon til religiøs praksis i sykehjemmet. Det kan virke som at sykepleierne favoriserte generell åndelig omsorg ut fra subjektiv kunnskap, men ga mindre oppmerksomhet til spesiell religiøs åndelig omsorg. En annen utfordring var opplevelsen av manglende kunnskap i utførelsen av åndelig omsorg. Det var heller ikke vanlig å snakke om eller innlemme åndelig omsorg i demensomsorgen i sykehjemmene, fordi kulturen i liten grad var åpen for å diskutere åndelige og religiøse spørsmål.

# List of original articles

- I. **Ødbehr, L.S., Hauge, S., Danbolt, L.J., Kvigne, K.** (2015). Patients' and caregivers' views on spiritual care, and their understanding of spiritual needs in persons with dementia: a meta-synthesis. *Dementia: the international Journal of social research and practice*. Article ID: DEM-15-0136
  
- II. **Ødbehr, Liv Skomakerstuen; Kvigne, K., Hauge, S., Danbolt, L.J.** (2014). Nurses and care workers' experiences of spiritual needs in residents' with dementia in nursing homes: a qualitative study. *BMC Nursing*, **13**:12. <http://www.biomedcentral.com/1472-6955/12>
  
- III. **Ødbehr, L.S., Kvigne, K., Hauge, S., Danbolt, L.J.** (2015). Spiritual care within dementia care: focus group interviews of how nurses and care workers carry out spiritual care in nursing homes. *BMC Nursing*. Article ID: MS: 1331937256173765
  
- IV. **Ødbehr, L.S., Kvigne, K., Hauge, S., Danbolt, L.J.** (2014). A qualitative study of nurses' attitudes towards and accommodations of patients' expressions of religiosity and faith in dementia care. *Journal of Advanced Nursing*. [doi: 10.1111/jan.12500](https://doi.org/10.1111/jan.12500)

# Abbreviations

COREQ	Consolidated Criteria for Reporting Qualitative Research
care workers	LPNs, auxiliary nurses, healthcare workers, assistant nurses, healthcare professionals
DNK	Church of Norway
ICN	International Counselling of Nursing
LPN	licensed practical nurse
NSD	Norwegian Social Science Data Services
NT	New Testament
OT	Old Testament
RN	registered nurse
SSB	Statistics Norway
WHO	World Health Organization
WMA	World Medical Association

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# 1 Introduction

The main purpose of this doctoral thesis is to explore how nurses (registered nurses [RNs]) and care workers (licensed practical nurses [LPNs], auxiliary nurses, health workers, assistant nurses) carry out spiritual care in nursing homes, by focusing on their experiences and perspectives of the spiritual needs of people with dementia.

Spiritual care is a dimension of nurses' holistic care (Dossey Selander, Beck, & Attewell, 2005; O'Brien, 2011), including mental, physical, social and spiritual dimensions (Delgado, 2005; Eriksson, 1987, 2010; International Council of Nursing [ICN] 2012; McSherry, 2006a). Studies show that nurses experience uncertainty about how to relate to the spiritual dimension of patients' lives and how to carry out spiritual care in practice (Lundmark, 2006; McSherry & Jamieson, 2013; Sessanna, Finnell, Underhill, Chang & Peng, 2011). In addition, research reveals that, although patients express their spiritual needs to nurses, their spiritual needs are not always met in care situations (Cook, Breckon, Jay, Renwick & Walker, 2012; Nixon, Narayanasamy & Penny, 2013). This seems even more challenging in dementia care, because many patients with dementia are unable to communicate their spiritual needs themselves, making spiritual care demanding for nurses (Killick, 2004). This research gap needs to be taken seriously and investigated further by research.

Dementia is a growing challenge worldwide (World Health Organization [WHO], 2012a). Its incidence is increasing in all the countries of the world (WHO, 2012a). Most people in nursing homes who have dementia rely on continuous care, depending on a comprehensive caring approach by nurses that may safeguard their care needs throughout the day (Bursell & Mayers, 2010; Ramezani, Ahmadi, Mohammadi & Kazemnejad, 2014). Furthermore, there are few guidelines for nurses in practice that deal with spiritual care for people in nursing homes who have dementia. The structure of this thesis is as described below.

Chapter 2 starts with a presentation of nursing homes as a research arena, the characteristics of dementia, and the perspective of caring needs for people in nursing homes with dementia. Thereafter, present perspectives on research into spirituality, spiritual needs and spiritual care, as revealed in nursing research and psychology of religion. Chapter 3 offers an overview of the main aims for the dissertation and the aim in the four substudies (I, II, III and IV). In Study I we created research to explore patients' and caregivers' views on spiritual care and

their understanding of spiritual needs in persons with dementia. Study II focuses on the experience of nurses and care workers of patients' spiritual needs, and Study III on the nurses' and care workers practice of spiritual care. Study IV explores difficulties for nurses in accommodating patients' expressions of religiosity and faith, and highlights some areas that the nurses and care workers experienced as challenging. Chapter 4 provides an explanation of the methodology used, and Chapter 5 gives a detailed description of the research design and methods used. The main findings in the four substudies are presented in Chapter 6, which lead to the discussion in Chapter 7. Here I also discuss methodological issues that have influenced the overall work of the dissertation. In conclusion, Chapter 8 provides some essential descriptions of spiritual care within dementia care in nursing homes. The implications for nursing practice are discussed in Chapter 9, and the thesis ends with some suggestions for further research in Chapter 10.

The term 'patient' is used in the thesis and the terms 'residents' and 'patients' in Studies I, II, III and IV. Furthermore, the term 'nurses' is used to cover both the group of nurses (RNs) and the care workers (LPNs, auxiliary nurses, healthcare workers and assistant nurses) throughout the whole thesis, apart from in Chapters 3 and 5. This results from a simplification in presentation of the findings and from the data being created jointly in the interview situations. Furthermore, the project has not attempted to distinguish between the perspectives of the nurses and the care workers, but has treated the data from the focus-group interviews as a whole.

## 2 Background

This chapter starts with a description of Norwegian nursing homes and an account of the characteristics of dementia. Thereafter, the concept of spirituality is elaborated upon, including spiritual needs and spiritual care, based on research in nursing and the psychology of religion. Then a presentation of spiritual care for people with dementia is provided, with reference to the state of the research field at the time the project started. The chapter ends with a summary and rationale for the dissertation.

### 2.1 Nursing homes and dementia

There are currently approximately 40 000 beds in old age care homes and nursing homes in Norway (Norwegian Ministry of Health and Care Services, 2013). Research shows that 80% of residents living in Norwegian nursing homes have dementia, although not all residents are necessarily diagnosed (Selbaek, Kirkevold & Engedal, 2008). The proportion of people living in Norwegian nursing home institutions aged between 80 and 84 years is slightly below 10% of the total, which means that the largest group of residents numerically in nursing homes is those aged 90 years and over (Statistics Norway [SSB], 2013). Women represent more than half of all residents of long-term institutions in Norway. Statistics Norway (2013) reveals that female residents, aged 80–89 years, represent 71% of the total, and of those aged 90 years and over, women account for 77% of the total. The Norwegian government's plans emphasized the importance of investing in small, adapted units for people with dementia in nursing homes (Norwegian Ministry of Health and Care Services, 2006). This means that, over the last few years, it has been a goal to make units in the nursing homes more like small housing entities (Norwegian Ministry of Health and Care Services, 2015).

#### **Dementia**

The World Health Organization (2012a) states that dementia is a public health priority. It has published research covering different aspects of dementia from all the continents of the world. According to the WHO (2012a), meeting the challenges associated with dementia is of growing interest and attention worldwide. Current estimates indicate that 35.6 million people worldwide are living with dementia; this number will double by 2030, and more than triple by 2050, affecting 115.4 million people (WHO, 2012a). The reasons are improved living

standards and longer life expectancy, especially in countries with low incomes and lower-middle-income countries, but also in countries in demographic transition (Chan, 2010; WHO, 2012a). The same trend is seen in Norwegian society. Recent statistics show that there are approximately 71 000 people with dementia in Norway (Norwegian Directorate of Health, 2014) and that the number will double by 2040 (Norwegian Ministry of Health and Care Services, 2006, 2007). The prevalence of dementia increases with age and in Norway the incidence is around 10 000 new cases each year (Gjerstad, 2013).

Dementia affects the brain through a degeneration of brain tissue and is usually progressive (Engedal, Haugen & Brækhus, 2009). The word 'dementia' comes from the Latin (*de*: without; *ment*: mind) and literally means 'to be away from his or her mind' (Gjerstad, 2013, p. 18). 'Mind' is related to the mental functions of the brain, which affect people's thoughts and personality (Talassi, Cipriani, Biancetti & Trabuccini, 2007). The literature differentiates dementia mainly into four major groups: (1) degenerative brain diseases such as Alzheimer's disease, (2) dementia with Lewy bodies, (3) frontotemporal dementia and (4) cerebrovascular dementia disease; these are the major contributors (Gjerstad, 2013). Dementia may also develop on the basis of other diseases (secondary dementia), such as post-traumatic events, alcohol abuse and/or other brain diseases (Gjerstad, 2013). The prevalence of dementia in the west lies between 5 and 10%, and Alzheimer's disease is the most frequent of the various dementias and makes up 60–70% of cases (Engedal, 2000; Marcusson, Blennow, Skoog & wallin, 2003).

In the following, some of the common challenges for people with dementia that occur during development of the disease are presented, with no differentiation according to a specific dementia diagnosis. The reason for the collective referral to dementia is that the level of patient functioning has not been an issue in this project, which did not intend to compare different forms of dementia. Furthermore, changes in patients' functioning and behaviour in the later phases of dementia are more common than in the early stages, due to more widespread brain damage.

In this dissertation, the focus has been on how nurses provide spiritual care in relation to their perspectives and experiences of patients' needs and spiritual expression. Nurses' knowledge of the characteristics of dementia is important in relation to how they meet and observe patients' individual needs. Dementia is characterized by failure of at least one mental function

that affects cognition or daily life function, or by lack of control of behaviour, emotions or motivation (Engedal & Haugen, 2004; WHO, 2012a, 2012b). This can result in poor understanding of language in terms of difficulties with learning and memory, where the episodic and semantic memory are impaired and can, in turn, cause an implicit or global memory impairment. This is apparent in terms of reduced conceptual understanding, concept formation, problem-solving or reasoning. Other areas of the brain affected are often the language centre, which leads to an impaired ability to communicate or various forms of aphasia (Engedal et al., 2009; Gjerstad, 2013). Dementia may also cause decreased perceptual functions and contribute to difficulties for patients in terms of identifying objects, distinguishing a figure from the background, or seeing how objects or drawings are constructed. Agnosia occurs frequently and is described as the inability to recognize/ understand perceptions in terms of understanding the visual and auditory sensory input or the object's significance/meaning. This can lead to impaired attention and imagination. Apraxia is a reduced ability to perform a voluntary action, and may take the form of swallowing problems during meals or inability to perform an action (Falchok et al., 2013). The executive functions are usually defined as cognitive and mental processes that underpin a flexible and goal-oriented behaviour (Engedal et al., 2009; Gjerstad, 2013), which is the case for those with frontotemporal lobe dementia (Possin et al., 2013). Many of those affected with dementia struggle with impaired emotion regulation, which can result in, for example, fear, anger, hatred, disgust, sadness, joy, love or happiness. This may appear in difficult care situations where patients have hallucinations, delusions, misinterpretations, aggression or irritability. The behavioural and emotional symptoms can also manifest themselves in the form of depressive symptoms, apathy, withdrawal or restlessness (Engedal et al., 2009; Gjerstad, 2013). Dementia involves a life change through altered sensory experiences that impair the patient's ability to consider the consequences. Cognitive decline can easily contribute to confusion and anxiety, and the patient's social life is reduced (Engedal et al., 2009). Furthermore, patients' experiences of fear, panic chaos, rage and despair are common (McKeith & Cummings, 2005). In the last phase of the disease, most people with dementia are entirely dependent on care, unable to attend to their own personal care (Engedal & Haugen, 2004).

The complex needs of people with dementia, as described above, indicate that they are a highly vulnerable group of people. Caring for people with dementia is generally demanding, because of patients' loss of function, which makes spiritual care even more challenging. The

great care needs in people in nursing homes who have dementia require a holistic nursing approach, because these patients are characterized by many challenges of a physical, social, mental and spiritual nature (McSherry, 2006a).

The clarification of the meaning of spirituality in nursing is of importance to appreciate patients' spirituality and exercise spiritual care in practice (McSherry, 2006a, 2006b; McSherry, Cash & Ross, 2004). A question is how research addresses spirituality. The following provides an exploration of spirituality, spiritual needs and spiritual care.

## **2.2 Theoretical perspectives on spirituality**

The origin of the term 'spiritual' is from the Latin '*spiritualis*', which means 'breath' or 'wind' (Agrimson & Taft, 2009; Buck, 2006; Delgado, 2005). The Latin word '*spiritualis*' describes a person of the 'spirit' (Guttu, 2005). 'Spiritual' in the Old Testament [OT] is described as '*ruach*' (which also means 'wind' in Hebrew) and in the New Testament [NT] by the Greek word '*pneuma*' (Hill et al., 2000). In order to expand on the clarification of the concept of spirituality, I have explored different descriptions of spirituality from research in nursing and psychology of religion. The latter is a discipline and research area in which different psychological theories and methods for studying human faith, belief and behaviour are applied (Danbolt, 2014; Danbolt, Engedal, Hestad, Lien & Stifoss- Hansen, 2014). The discipline is primarily grounded in psychology, but embraces other disciplines such as nursing, medicine, anthropology, sociology, theology, religious studies and pedagogy (Danbolt, 2014). The clinical psychology of religion seeks to understand how faith and beliefs gain different meaning in people's lives, during times of illness and suffering (Danbolt, 2014). The main issue for the use of psychology of religion, together with nursing research, as the theoretical foundation in this thesis was the psychology of religion's broad anchoring in research. Below are examples of similarities and differences in the descriptions of spirituality in nursing and in psychology of religion.

Several conceptual analyses of spirituality have been conducted in nursing research, especially in the last two decades (Buck, 2006; McBrien, 2006; Newlin, Knafl & Melkus, 2002; Pesut, Fowler, Taylor, Reimer- Kirkham & Sawatzky, 2008; Tanyi, 2002). Analysis of the concept of spirituality has resulted in an inexhaustible set of defining characteristics of spirituality (Clarke, 2009). However, attempts to clarify the concept of spirituality have not

reduced the uncertainty of the term's content, making the whole field complex to understand (McSherry & Cash, 2004; McSherry et al., 2004). One reason is that spirituality is described from different theoretical traditions, such as spirituality as particular religious practices or spirituality in more general terms (Koenig, 2008). The description of spirituality thus emerges as non-specific in research (Höcker, Krüll, Kock & Mehnert, 2014). A question is whether the vagueness may have contributed to making the boundaries of the psychosocial, psychological and spiritual dimensions in nursing indistinct? Furthermore, there has been a long and extensive discussion in interdisciplinary research, as well as in nursing research, about the content and the relationship between the concepts of spirituality and religiosity (Zinnbauer & Pargament, 2005). Similar discussion is seen in psychology of religion, dealing with the inequalities of concepts, and which of the terms is the broadest and most comprehensive (Zinnbauer & Pargament, 2005). This discussion is still ongoing (Ramezani et al., 2014). In this thesis, spirituality is considered as the broader concept and religiosity as a subordinate term, which means that religiosity is a form of spirituality linked to a particular religion.

During the efforts to clarify the understanding of the concept of spirituality, the psychologist Kennet I. Pargament's (2007) definition applies as a foundation, as well as that of Pamela Reed (1992) from nursing research. Pargament (1997) considers religiosity as an overarching concept in the account of the term 'spirituality', which is another position that is assumed in this thesis. As long as I have been clear in my position in relation to descriptions of spirituality and religiosity, I have not considered them contradictory. In the following is a presentation of Pargament's (2007) definition of spirituality, followed by Reed's (1992) definition in more detail.

### **Spirituality as a search for the sacred**

Pargament (2007, p. 32) defines spirituality as the 'search for the sacred'. He describes the 'sacred' as an inner experience and the highest of human potentials or the 'essence and core of spirituality' (Pargament 2007, p. 43). Core concepts describing the sacred are concepts of God, a higher power, divine being or the transcendent reality. Sacred qualities consider something boundless, a perception of endlessness in time and space (Pargament, 2007). The sacred evokes the most fundamental in human experience, something real or ultimate, expressed through relationships filled with love and compassion. The sacred refers to something that humans regard as worth reverence and respect (Pargament, 2007). Search is,

in this perspective, a dynamic and active process (Pargament, 1997; Pargament & Mahoney, 2002), and means an intentional movement towards something meaningful or significant (Pargament, 2007). The sacred may be a representation of anything to which a person gives value in life, e.g. 'objects' (Pargament & Mahoney, 2005). 'Objects' may be people, places, books, houses, or sacred experiences and events (Danbolt, 2014). They are considered sacred because people attribute sacred characteristics to them and interact with these objects with respect. The interaction may occur individually, in groups or by the society and/or in that culture (Danbolt, 2014). Furthermore, Pargament (1997) claims that religiousness is 'a search for significance in ways related to the sacred' (p. 32), and is an ongoing process through the whole lifespan (Pargament, 2013; Pargament et al., 2013). Pargament (1997) explains 'significance' as it involves people's set of values, something meaningful of great concern. These concerns relate to psychological conditions such as shelter or safety, or it can be social concerns such as health and well-being (Pargament et al., 2005). In addition, concerns might relate to material things such as buildings and symbols (Zinnbauer & Pargament, 2005).

The argument that spirituality is a 'search for the sacred' (Pargament, 2007, p. 32) provides some frames in conceptual understanding. Pargament (2007) highlights the human search intentionally, and spirituality's concerns with human values, faith and belief systems. Pargament's (1997, 2007) focus on the sacred may complement descriptions of spirituality in nursing research, because 'the sacred' is not much focused on in definitions of spirituality. During Reed's (1992) presentation of spirituality from a nursing perspective, continuing attention of research in psychology of religion offers elaboration of the concepts in the definition.

### **Spirituality as the propensity to make meaning**

Pamela Reed (1992) claims from a nursing perspective that spirituality means the following:

Spirituality refers to the propensity to make meaning through a sense of relatedness to dimensions that transcend the self in such a way that empowers and does not devalue the individual. This relatedness may be experienced intrapersonally, interpersonally and trans-personally. (p. 350)

Reed's (1992, 2014) definition of spirituality emphasizes in particular the concept of 'meaning', 'self-transcendence' and 'relatedness'. The following gives an account of the three key concepts in Reed's definition.

## **Meaning**

The experience of meaning is achieved in different ways in human lives. Reed (1992, 2014) elaborates only to a limited extent on the understanding of the content of 'meaning'. She looks at human meaning making as an experience of self-transcendence. One question is whether this perspective is too narrow, so it is useful to broaden the perspective on meaning making by applying insight from close disciplines. Research on meaning making from a psychological perspective reveals that people's meaning making is complex and takes place at different levels of human perception and actions (Park, 2010; Schnell, 2010). From a social-psychological perspective, meaning can be understood as "a mental representation of possible relationships among things, events, and relationships. Thus meaning connects things" (Baumeister, 1991, p. 15). Furthermore, experience of meaning may be linked to specific situations or particular environmental encounters (situational meaning) or to human general orienting systems that are influenced by beliefs, goals and subjective feelings in life (global meaning) (Park, 2010).

The psychologist Tatyana Schnell (2011) states that people recognize some vital 'sources' contributing to meaning during their lifetime that are more important than other sources. Here, Schnell (2011) brings in vital knowledge to complement Reed's (1992) understanding of "relatedness to dimensions that transcend" (p. 350) in human lives, as well as Reed's perspectives of spirituality as a "propensity to make meaning" (Reed, 1992, p. 350). People may experience meaning in relation to nature, silence, relationships with other people, music, culture and/or traditions (Danbolt, 2014; Schnell, 2011). Experiences of meaning refer to either individuals' global meaning or situational meaning (Park, 2010). Schnell (2011) uses the word meaningfulness, which means "an appraisal of one's life as coherent, significant, directed and belonging" (p. 669). One concern is when discrepancies arise in human lives, such that the person no longer experiences meaning as previously. What kind of dimensions, or sources, do people then draw on to regain a sense of meaning? Schnell (2011) refers to five areas of meaning making in human lives based on empirical research. "Well-being and relatedness", means cultivating and enjoying life's pleasures in privacy and company

(Schnell, 2011, p. 669). “Order” refers to a source of making meaning in the form of holding on to values, decency, and what is tried and tested in human lives (Schnell, 2011, p. 668). “Self-actualization” is achieved through ‘employing, challenging, and fostering one’s capacities’ (Schnell, 2011, p. 668). “Vertical oriented self-transcendence” is characterized by the person’s orientation towards an immaterial, supernatural power explained as explicit religiosity, faith in a personal God and spirituality in the form of a belief in a supernatural reality (Schnell, 2011, p. 668). With “horizontal self-transcendence”, the person takes responsibility for (worldly) affairs beyond his or her immediate concern, where the ability to generate stands as the strongest predictor (Schnell, 2011, p. 668). Schnell’s (2011) research does not have spirituality as a starting point, but rather the concept of meaning making. Nevertheless, based on Reed (1992) and Pargament (2007), the concept of meaning is essential to the understanding of spirituality.

## **Transcendence**

The next core concept in Reed’s (1992) definition is ‘transcendence’. Self-transcendence means ‘the capacity to expand self-boundaries in a variety of ways’ (Reed, 2014, p. 111). Self-boundaries mean human experience of physical, psychological or environmental restrictions, posed by a certain situation or different forms of limitations that the person experiences (Reed, 1991a, 1991b; Reed & Runquist, 2007). Reed’s (1992) definition of spirituality emphasizes that the experience of self-transcendence as expanding self-boundaries empowers and does not devalue the individual. Self-transcendence is associated with positive experiences in human lives, and is therefore not of neutral value. Reed’s (1992) definition does not discuss the fact that some people may associate spirituality with negative experiences. Descriptions of such negative experiences are the fear of death, or anxiety relative to annihilation, or hell (Stålsett, 2014).

The psychology of religion provides some nuances to the nursing research in the conceptual understanding of transcendence. Pargament (2007) describes ‘transcendence’ as ‘something out of the ordinary in a particular object or experience’ (p. 39). The experience of transcendence defines not something negative or positive, but rather something that exceeds. Schnell (2011) supports Pargament’s (2007) description of self-transcendence by arguing that it means a ‘commitment to objectives beyond one’s immediate needs’ (Schnell, 2011, p 668). Thus, self-transcendence is associated with experiences that are not just related to needs or

self-boundaries in human life. Psychology of religion thus contributes an expanded perspective on self-transcendence that complements Reed's (1992) description.

## **Relatedness**

Reed's (1992) definition of spirituality points to a sense of relatedness in people's lives, but the term 'relatedness' is not elaborated on in a comprehensive way. 'Relatedness' can be considered a form of 'holding on to' or 'sticking to', but these concepts do not contain exactly the same meaning. The relatedness might be experienced intrapersonally, interpersonally or transpersonally (Reed, 1992). With relatedness experienced intrapersonally there is a connectedness within oneself, and increased awareness of one's world view, values and dreams. With an interpersonal relatedness the focus is on connecting the person to other people through relationships, and participating in social events or the natural environment, which refers to a horizontal dimension. The relatedness that is experienced transpersonally is the person's possibility of connecting with dimensions beyond the typically discernible world, and strategies to connect with God, a power or a purpose greater than oneself (Reed, 2014). This refers to a vertical dimension of connectedness (Reed, 2008, 2009; Schnell, 2011). Both Pargament (2007) and Reed (1992) relate to people's search for significance and meaning as an important aspect in the understanding of spirituality. Reed's (1992) use of the word 'relatedness', and Pargament's (2007) use of the word 'search', might contain some of the same intentional meaning.

In Register and Herman's (2010) understanding, connectedness means, "the ultimate expression of human existence that comes from within and determines how people engage in the world" (p. 58). Connectedness is thus a multidimensional and personal experience (Cooney, 2014; Register & Herman, 2010). Out of this, human relatedness to 'dimensions that transcend the self in such a way that empower and does not devalue the individual', in line with Reed (1992, p. 350), leads to different forms of connectedness and an experience of spiritual well-being. However, there is no description of what constitutes the term 'dimensions' in Reed's definition, other than that 'dimensions' stand in a relation to 'making meaning'. What distinguishes Reed's (1992) and Pargament's (2007) perspectives on spirituality is *what* makes meaning in human lives. Pargament (2007) is clearer in his description than Reed (1992), claiming that people search for dimensions that are associated with a specific value (e.g. sacred). So far, Reed's (1992) definition has revealed that

spirituality is a form of meaning making through self-transcendence, experienced as an interconnectedness within the individual (inwards), others/environment (outwards) and towards God/a deity (upwards). Reed's (1992) definition in research has highlighted significant aspects in the conceptual understanding of spirituality, and research in psychology of religion contributes to an extended perspective on spirituality by focusing on the 'sacred'.

In summary, based on the research in both nursing and psychology of religion, 'spirituality' is characterized by human search for the sacred and experiences of self-transcendence and connectedness (to self, to others and to God/a deity), where the end point is the human experience of meaning. This understanding of spirituality is the backdrop for this thesis. The question is which elements of this understanding of spirituality are recognizable in the descriptions of spiritual needs and spiritual care in nursing research and psychology of religion.

## **2.3 Spiritual needs**

According to Narayanasamy (2004), spiritual needs are important to all people regardless of age or human conditions, because they are part of basic human nature. Descriptions of spiritual needs, includes much of the same concepts as for descriptions of spirituality. Spiritual needs in research are associated with the human need for reconciliation and the need to forgive others (Chiu et al., 2004; Pesut, 2013; Pesut et al., 2008; Ross, 2006; Sessanna et al., 2011; Vilalta et al., 2014). Experiences of reconciliation may lead to, or preserve, loving and harmonious relationships and experiences of trust (Agrimson & Taft, 2009; Buck, 2006; Delgado, 2005; Narayanasamy, 2004). Nixon et al. (2013) found in their study of patients' spiritual needs that the need to talk to other people about spiritual concerns was important, as well as the need to have hope for the future.

Furthermore, descriptions of spiritual needs in research emphasize the need to experience meaning and purpose in life (Narayanasamy, 2004). Several research studies in both nursing research and psychology of religion emphasize spiritual needs representing the human need to express faith, experience transcendence, or serve and worship God or a higher power (Hodge et al., 2012; McEwen, 2005; Narayanasamy, 2004; Nixon & Narayanasamy, 2010; Snider & McPhedran, 2014).

Erichsen and Bussing (2013) conducted a study among 100 elderly people living in nursing homes (mean age 84) and handed out a standardized questionnaire, 'Spiritual Needs Questionnaire', to the participants. The findings in the study revealed that most of the residents wanted to connect with friends and family members, but that they were afraid that family members had limited interest in their concerns. The need for giving, formulated as the need to be able to generate, was of the highest relevance with regard to the participants' experience of spiritual needs (Erichsen & Bussing, 2013).

Nurses' spiritual care aims to meet patients' spiritual needs (McSherry, 2006a). The following provides a description of spiritual care as it emerges in nursing research, with support from research in psychology of religion.

## **2.4 Spiritual care**

Research on spiritual care in nursing and psychology of religion reveals that spiritual care is described from different theoretical perspectives (McSherry & Jamieson, 2011; Puchalski & Ferrell, 2010; Ross, 2006). The presentation of spiritual care in the following is organized under three main headings: (i) general spiritual care, as a consequence of considering spirituality as a broader concept; and (ii) particular religious spiritual care, as a consequence of considering religiosity as a subset to spirituality. Thereafter, a presentation of research on spiritual care in dementia care is offered under the heading (iii) empirical research on spiritual care in dementia care. At the end of the presentation there is a synopsis of spiritual care in nursing.

### **General spiritual care**

Spiritual care means assisting people in their search and need for meaning in life (Koslander, da Silva & Roxberg, 2009; Nixon et al., 2013). People question the meaning of suffering, loss, grief and loneliness in many of life's stages, particularly during the experience of severe disease (Pargament, 2007). A relevant question is how nurses may help people in their search for meaning, as part of spiritual care (Baumeister, 1991; Baumeister, Masicampo & Twenge, 2013).

Spiritual care must be based on the patient's own experienced and expressed reality, whatever needs the patient acknowledges (Edwards, Pang, Shiu & Chan, 2010). Sawatzky and Pesut (2005) reveal a similar perspective through their definition of spiritual care: "Spiritual nursing care is an intuitive, interpersonal, altruistic, and integrative expression that rests on the nurse's awareness of the transcendent dimension yet reflects the patient's reality" (p. 30).

Several descriptions of spiritual care are in line with the definition of Sawatzky and Pesut (2005), as referred to in the following. Timmins, Neill, Graffin, Kelly and De La Cruz (2014) emphasize that spiritual care means listening to people, displaying concerns, demonstrating cheerfulness and comforting when interacting with patients. Spiritual care means showing kindness and spending quality time with people, and meeting people's questions relating to their identity. This description reflects the importance of nurses' respectful attitude. In addition, nurses must have attributes such as compassion and empathy to provide spiritual care (Monareng, 2012). Spiritual care is described furthermore as supporting humans in their decisions and questions about life and death, encouraging and helping people to find a purpose in life when needed (Baldacchino, 2006; Koenig, 2007; Nixon et al., 2013). It is thus described as an interpersonal relationship, and that nurses in such relationships need to reassure the person (McSherry & Jamieson, 2011). It implies that nurses assist individuals in their attempt to make sense of life's circumstances (McSherry & Cash, 2004; McSherry et al., 2004) and meet the person's isolation and withdrawal in an appropriate manner (Ross, 2006), as well as to give hope to the person's life (Ramezani et al., 2014). Several of these descriptions of spiritual care in research seem to deal with safeguarding the individuals' values as a form of altruistic care, in line with Sawatzky and Pesut's (2005) description.

Although the descriptions in research may refer to key aspects of spiritual care, a weakness is that they provide few guidelines for nurses in practice (Timmins et al., 2014). The same characteristics are revealed in Sawatzky and Pesut's (2005) definition, which refers to nurses' intuitive, interpersonal, altruistic and integrative expressions. The meaning of intuitive expressions might be interpreted as a spontaneous responsiveness in the nurses' interaction with the patient. From Sawatzky and Pesut's (2005) perspective nurses providing spiritual care may require maturity and the ability to comprehend other people's spirituality. Nevertheless, it could be challenging for nurses who have little professional working experience in general, and little work experience of spiritual care in particular. In addition, this becomes difficult for nurses who are not familiar with the spiritual realm and lack

knowledge about spiritual care in general; this leads to them feeling uncertain how to meet the spiritual needs of other humans (Lundmark, 2006).

### **Particular religious spiritual care**

Descriptions of particular religious care in research refer to nurses helping people in their attempt to express their faith and beliefs (Paloutzian & Park, 2005; Rykkje, Eriksson & Raholm, 2013; Zinnbauer & Pargament, 2005). Furthermore, religious care aims to help people during their search for religious experiences (Cheraghi, Manookian & Nasrabadi, 2014; Hodge et al., 2012; Reimer-Kirkham, 2014). This is in line with Schnell's (2011) research in which she claims that a strong predictor for meaningful experiences in people's lives emerges from the possibility of expressing faith and religiosity.

How nurses deal with religious care encompasses them showing a respectful attitude towards patients' religiosity (Koenig, 2008; Ross, 2006). Nurses helping people with religious practices means assisting people in prayers, reading Holy Scriptures or participating in religious rituals such as worship and singing. Furthermore, religious care means helping people express their belief systems which are either chosen or handed down through individual and/or cultural heritage (Farran, Paun & Elliott, 2003; Group, 2006; Tanyi, 2002; Underwood-Gordon, Peters, Bijur & Fuhrer, 1997). Religious care includes talking with the patients about questions of eternal life, and guiding people in reflections about God's presence during times of suffering (Nixon et al., 2013; Rykkje et al., 2013). O'Brien (2011) states that nurses must take time in allowing the patient in their care to express ethical or philosophical views, as well as any fears and anxieties related to a religious belief system/view of life. The nurse must be spiritually supportive, assisting patients whenever it is within the realm of his or her understanding or expertise (O'Brien, 2011).

It is found in research that religiosity counteracts apathy (AbdAleati, Mohd Zaharim & Mydin, 2014) and stress (Pargament & Park, 1997; Pargament, 2011), and even has a positive impact on people's depression (Bonelli & Koenig, 2013). Miller and Thoresen (2003) state that much of the research has been directed at finding the negative impact of religion in people's lives, but it is important to consider both the negative and the positive aspects of religiosity carefully.

I have now referred to research that describes spiritual care for people who are cognitively healthy. In the following gives an account of descriptions of nurses' and healthcare personnels' spiritual care for people with dementia as it appeared at the start of this project.

### **2.4.1 Empirical research on spiritual care in dementia care**

We initially conducted a literature search on spiritual care in dementia care in 2010. The databases used were: Cochrane Library, MEDLINE, British Nursing Index, PsychINFO, Embase and CINAHL. The search terms in all databases were: spiritual care OR pastoral care OR religion AND dementia OR nursing home AND nurses practice OR elderly care. The following free text keywords were also used: elderly, spirituality, spiritual care, nursing home, beliefs and dementia. The search result was 325 articles.

The further processing and selection of articles were conducted by assessments of abstract, headings, subject matter in accordance with the inclusion criteria and the theoretical relevance. The general inclusion criteria were that studies had to be peer-reviewed, primary, empirical, qualitative studies or theoretical papers, published between 1995 and 2010, written in English, Norwegian, Swedish or a Danish language, with abstracts available, and a practitioner's perspective on nursing homes. This implied that studies with outcomes such as quality of life and religious coping were not included for investigation. All articles with a quantitative design were excluded, as well as book reviews, dissertations and duplicates. There were few empirical studies from a nurse's perspective in nursing homes available for investigation. During the selection process, we discovered only two primary empirical studies that included nurses in their sample (Dinning, 2005; Goodall, 2009). Seven theoretical papers explored spiritual care in dementia nursing in institutions from an interprofessional perspective (Bephage, 2009; Killick, 2004; Lawrence, 2003; Lloyd, 2004; MacKinlay, 2006; Ruder, 2009; Vance, 2004). We included these nine articles for further investigation.

Reading the studies closely, we identified content issues as expressed by the original author. We started reading the articles by converting extracted descriptions of spiritual care into categories, facilitating the distinction of patterns, themes, variations and relationships (Whittemore & Knafl, 2005). They were compared item by item so that similar descriptions were categorized and grouped together, based on three different types of experience from the primary studies: (i) carers' attitudes to spiritual care, (ii) carers' practice in delivering spiritual care, and (iii) carers' knowledge of and perspective on this form of care (Whittemore &

Knafl, 2005). We then investigated how the studies in the same thematic group were related, and processed each of them into the grid, maintaining the terminology from the original paper; thus we compared the content issues from each study on the basis of the subgroup perspective (Larun & Malterud, 2007; Malterud, 2002; Whittemore & Knafl, 2005). After organizing the core issues for each paper, we looked across the grid and related them to each other. Then we tried to identify patterns, themes and relationships, and synthesized them into a new description, which was adequate and used broader terms (Larun & Malterud, 2007). The final step of the analysis was extrapolating the verification from the description of patterns to a higher level of abstraction. Furthermore, for each subgroup a conclusion was made in an integrated summation of the topic (Whittemore, 2005). The findings of this integrative literature review have been published in a Norwegian journal (Ödbehre et al., 2012). The study is not included in this dissertation, but below I refer to the summary of the findings of the integrative literature review as to the status of the research when this doctoral project started. Spiritual care within dementia care in research comes under the following headings: (i) general spiritual care, in the form of *meeting patients' need for coherence in life*, and *increasing patients' well-being through sensory stimulation and memory work*, and (ii) particular religious care in the form of *facilitating religious activities*. The designation for the occupational groups in the research presentation is 'nurses'.

### **General spiritual care**

*Meeting patients need for coherence in life.* The findings highlight the asymmetrical relationship between nurses and patients, making the nurses ensure responsibility for the relationships with patients in terms of creating safety and comfort (Bephage, 2009). Good relationships between nurses and patients were considered important for patient experience of cohesion with self and each another (Goodall, 2009). The communication skills of the nurses, through showing respect when they interacted with patients, were part of spiritual care (Goodall, 2009; Killic, 2004; Lloyd, 2004). Various studies also emphasized that nurses should show compassion and love towards patients, which was seen as vital for patients' ability to maintain a sense of hope (Goodall, 2009). Several of the studies included in the literature review referred to the importance of nurses' attitudes towards people with dementia, and their ability to confirm patients' personhood when describing spiritual care (Bephage, 2009; Lloyd, 2004; Ruder, 2009). The studies included revealed that spiritual care meant seeing the person behind the dementia, the symptoms and the behaviour, and the nurse trying

to familiarize herself with the patient's perspective (Killick, 2004). A weakness in the findings is that the studies gave few descriptions of what nurses did or how they reflected when they tried to familiarize themselves with patients, and achieve safety and comfort in the relationships.

*Increase patients' well-being through sensory stimulation and memory work.* Spiritual care as a sensory stimulation was a way of increasing patients' well-being. Stimulation of the senses could be achieved through artistic activities such as painting pictures, meditation, and use of music, singing hymns and songs (Bephage, 2009; MacKinlay, 2006; Vance, 2004). Nurses' understanding of spiritual care was linked to memory work, which contributed to experiences of 'meaning' (Bephage, 2009; Lawrence, 2003). Meaning was achieved through the activities themselves, and also through the sense of peace and well-being. The studies included did not discuss how or why the activities achieved meaning in the patients' lives, or how they interpreted the experiences of meaning.

### **Particular religious spiritual care**

*Facilitating religious activities.* Spiritual care was conveyed by nurses facilitating religious activities for the patients, such as prayer or devotions for those who wanted them, holding and reciting a rosary or sacred objects (Bephage, 2009; Ruder, 2009; Vance, 2004). The findings in the included studies also indicated that spiritual care was vital for patients' sense of quality of life and to find meaning and intimacy with God (Lawrence, 2003; MacKinlay, 2006). An important question that the studies did not discuss in a convincing way was how people with dementia experience quality of life, and how nurses interpreted patients' expressions.

The overall impression of the literature review indicated that the characteristics of spiritual care in dementia care were described from a broad perspective, because much seems not to be rooted in a unified understanding of the nature of spiritual care. This difficulty raises many unanswered questions that need to be addressed further about the impact of spiritual care on people with dementia.

### **2.4.2 Summary**

This chapter reveals that nurses' spiritual care means being aware of the other person's reality or life world (Sawatzky & Pesut, 2005). This is possible through nurses' attentiveness to the

transcendent dimension of patients' lives, and through experiences of connectedness between nurses and patients (e.g. helping with the other people's connection to self, others, the environment and God) (McSherry & Jamieson, 2011; Reed, 1992; Sawatzky & Pesut, 2005). In Pargament's (2013) research, the intentional searching by humans for significance and the sacred is emphasized; this perspective complements the understanding of spirituality and spiritual care in relation to Reed's understanding in nursing (Reed, 2008, 2009, 2014). Psychology of religion has thus contributed to bringing expanded knowledge about both the content of the concept of spirituality and the dimension of meaning (Schnell, 2011) in human lives as part of spiritual care. Furthermore, the research has revealed that people need to express faith, beliefs and religiosity, and that spiritual care means facilitating such expressions.

Based on the research, spiritual care includes meeting the other person's expression of spirituality and spiritual needs. Furthermore, spiritual care means helping humans achieve meaning through supporting their search for the sacred, self-transcendence and experiences of connectedness, and safeguarding significant values by facilitating human expression of faith, beliefs and religiosity.

## **2.5 Rationale of the project**

Previous research has revealed that spiritual care means helping people achieve meaning (Reed, 1992). Furthermore, spiritual care also involves meaning achieved by experiences of transcendence and the sacred, and in appraisal of sources that give meaning to human lives (Pargament, 2007; Schnell, 2011). Research in dementia nursing does not seem to address the sacred and transcendence convincingly. Furthermore, research offers limited knowledge about how nurses observe the spiritual needs in patients' lives, especially for patients living in nursing homes. This makes demands on nurses to understand and interpret patients' expressions of spirituality and spiritual needs. Research reveals that expressions of religiosity and faith are important in many people's lives (Pargament, falb, Ano & Wachholtz, 2013). Most of the studies we initially investigated in the project focused on how nurses introduce patients with dementia to religious practice, or how patients reacted and answered directly to questions about spirituality. There seems to be a need for more knowledge related to an assessment of the significance of religious care for people with dementia.

There seems to be a limited amount of research exploring nurses' spiritual care of people in nursing homes with dementia. This issue needs to be investigated in nursing research. The aim of this project was therefore to address how nurses carry out spiritual care in nursing homes, by focusing on their experiences and the perspectives of the person with dementia spiritual needs.

# 3 Aims and research questions

The main purpose of this doctoral thesis is to explore how nurses RN's and care workers carry out spiritual care in nursing homes, by focusing on their experiences and perspectives of the spiritual needs of people with dementia.

## **Research question and aim of Study I**

The research question in Study I, related to how people with dementia and caregivers describe spiritual needs and spiritual care in empirical research.

*The specific aim of Study I:* To synthesize research that investigated how patients and caregivers view spiritual care, come to understand the spiritual needs of people with dementia and how caregivers provide care congruent with peoples' needs.

## **Research question and aim of Study II**

The research question in Study II related to how nurses and care workers recognize and experience spiritual needs in the lives of residents with dementia.

*The specific aim of Study II:* To investigate nurses' and care workers' experience of spiritual needs in residents with dementia in nursing homes.

## **Research question and aim of Study III**

The research question in Study III related to how nurses carry out spiritual care.

*The specific aim of Study III:* To investigate how nurses and care workers carry out spiritual care for people with dementia in nursing homes.

## **Research question and aim of Study IV**

The research question in Study IV related to how nurses in nursing homes address the religiosity and faith of people with dementia, and how they accommodate patients' religious expressions.

*The specific aim of Study IV:* To investigate nurses' attitudes towards and accommodation of patients' expressions of religiosity and faith in dementia care in nursing homes.

## 4 Methodology

This doctoral project is grounded in interpretative phenomenology and hermeneutics as the overarching methodology. In the attempt to understand nurses' perspectives and experiences, in their professional working life - world, we had to draw on knowledge from both phenomenology and hermeneutics. This chapter offers an account of the methodological considerations, together with the main perspectives within the phenomenological and hermeneutic philosophy that have been central to this work, and both the interviews and data sources in Studies II, III and IV and the analysis of the research literature in Study I.

### **Phenomenological and hermeneutic methodology**

The term 'phenomenon' means 'something that shows itself', or appears (Heidegger, 2007; Heidegger, Fried & Polt, 2010). Studies in interpretative phenomenology are based on the study of essences (van Manen, 1997b). The core essence of a phenomenon is described as 'the most essential meaning for a particular context' (Kleinman, 2004, p. 10). Interpretative phenomenology does not separate description and interpretations, but draws on insight from the hermeneutic tradition by arguing that all descriptions constitute a form of interpretation (Willing, 2013). The phenomenological attitude allows researchers to take a reflective position and question what they would usually take for granted. Phenomenology asks about the very nature of a phenomenon, and looks at it in many different ways until there is an expanded understanding of the phenomenon (immersion) (van Manen, 1997b). The phenomenological perspectives bring out the tension between what is previously known and what is reflected on and unique in the human experience of a 'life world' (van Manen, 1997a). Phenomenology aims to describe particular phenomena by gaining a deeper understanding of the nature of the meaning of experiences, its appearance or the life world as it is immediately experienced (Bradbury-Jones et al., 2009; Streubert & Carpenter, 2011). This means drawing on a shared familiarity in nurses' working life world, expressed through actions, narratives and reflections (Lindseth & Norberg, 2004). We asked the nurses in the current project: 'What is the experience of spiritual care like?'

In phenomenology research the reader meets people's lived experiences in textual expressions, where lived experiences present themselves in the light of the people's self-understanding (van Manen, 1997b). Social conditions and experience of the surrounding

world thus influence one's experience of both self and one's life world (Nortvedt & Grimen, 2004). By life world is meant the human encounter with the world, as the person faces it in daily life, independent of prior scientific explanations (Kvale, Brinkmann, Anderssen & Rygge, 2009). This may include people's experiences of self-awareness and/or self-confidence (Kohut, 2011). Humans constantly interpret themselves interacting with their experience in the surrounding world (Ricour, 1984).

The term 'hermeneutics' means understanding, learning or interpretation (Krogh, 2009). It can be said to have an 'inside' perspective, because hermeneutics is about creating mutual understanding between two parties – as, in this case, the reader and the text (Gadamer, Weinsheimer & Marshall, 2004). No understanding can exist in isolation (Gadamer & Jordheim, 2003). When faced by something new, people's basic perceptions and understanding of phenomena and things are vital for any new understanding. Understanding is primarily based on a self-understanding, along with the ability to understand others (Gadamer & Jordheim, 2003). An important question is what affects people's understanding. Gadamer et al. (2004) state that historical understanding influences human understanding. People carry their history with them in the face of new experiences. Any understanding presupposes another understanding, called pre-understanding (Gadamer et al., 2004). Pre-understanding affects people's beliefs and basic notions of life, and is based on experience, concepts and theories to which they give value (Gadamer et al., 2004). This connection between the past and the present is the actual understanding; without this reflection, it is impossible to achieve a comprehensive new understanding (Gadamer & Jordheim, 2003; Gadamer et al., 2004). Martin Heidegger (1926/1962) transformed Husserl's understanding of a human's 'life world' into 'being in the world', which meant that the pre-understanding should not be ignored, but rather considered as a foundation for new understanding (Heidegger, 2007). Basically, any new understanding requires an awareness and utilization of pre-understanding, attitudes and preferences in the face of the surrounding world (Gadamer et al., 2004). Pre-understanding is also a prerequisite for understanding the new through the pre-understanding being recognized and furthermore challenged. It is therefore not necessarily negative or inhibitory to have pre-understanding in the face of a text, assuming that the reader recognizes it and reflects on the content and consequences. Pre-understanding constitutes the very basis of the hermeneutic process.

People's pre-understanding and historical conditions constitute the 'human's horizon of understanding' (Gadamer et al., 2004). From this one can conclude that earlier horizons of understanding affect the newer generations through their effect history. This is possible when people relate to traditions connecting them with the past. The horizon of understanding is thus not fixed. From this perspective, understanding occurs when two different historical horizons of understanding get nearer, with the goal of merging. This assumes that the reader is willing to make an effort to understand in the face of any new and sometimes challenging information. At the same time, there is a realization that the human horizons of understanding may not be fully in unity (Krogh, 2009). This leads to another step in the encounter with the text. People understand concepts differently in different contexts, so the text must be processed as 'transparent' for the reader. The assumption is that the text contains a kind of hidden consciousness that needs to be uncovered. Based on this understanding, texts are self-contained and 'live their own lives' (Ricoeur, 1976). The basis is the idea that the text contains several possible interpretations that primarily emerge, because they can carry on its multiple meanings and messages, as well as the concepts possibly being separately ambiguous and with different emphasis.

Interpretation of the text means entering the hermeneutic circle (Lindseth & Norberg, 2004). Humans understand and interpret language and text in an interaction with the quest for meaning. Interpretations often contain explanations or build on them. In van Manen's (1997b) perspective, research is oriented towards interpreting the 'text' (of hermeneutics) that described the human 'lived experience' (phenomenology). Understanding, partly understanding and full appreciation are related in hermeneutic thinking (Gadamer et al., 2004). The hermeneutic circle is a circular movement between text parts and the whole text. Some speak of a spiral in which one is increasingly acquiring more knowledge about a topic (Gadamer et al., 2004). Three aspects are thus fundamental and essential to the interaction between reader and text: the text's description of the person's action, the meaning of the actual action and how the action 'speaks' to the reader (Ricoeur, 1976). The understanding of a pronounced action rests not on the experience itself, in isolation, but on the grasp of the essential meaning of the experience described. The understanding of the text is grounded in the movement from what the text 'says' to what it 'talks about' (Lindseth & Norberg, 2004). Ricoeur (Ricoeur & Thompson, 1981; Ricoeur, Hermansen & Rendorff, 2002) considers this the close connection between understanding and explanation, aiming for deeper insight, where the main purpose is the search for meaning.

In our work with the text, we tried to clarify our own understanding by not letting it dominate, but also by not completely putting it out of action either (Gadamer et al., 2004). We were nevertheless aware that this could be challenging if the values in our own lives as readers and the text content were opposed to each other. In such cases, parts of the interview text are discussed in the research group. Chapter 5 provides an overview of the methods used, their understanding, and the process of data collection and analysis.

### **Meta-synthesis**

The meta-synthesis (Study I) was inspired by Noblit and Hare's (1988) method of synthesizing primary qualitative research. We did not relate to the participants who were in the primary empirical studies that we included in the meta-synthesis, but to the findings in the included studies, based on the primary authors' interpretations and presentation of the findings. In Study I, we used methods from meta-ethnography – although not meta-ethnography as a methodology in the dissertation. For this reason, meta-ethnography is not elaborated on as an overarching philosophy of science.

In the empirical studies (Studies II, III and IV), the theoretical foundation for the studies was based on phenomenological–hermeneutic traditions (in Studies II and III) and a hermeneutic–phenomenological tradition (in Study IV). Both theoretical traditions were applicable in the research of experience and understanding among nurses. In Chapter 5, we provide descriptions on how we conducted the four studies in the dissertation (Studies I, II, III and IV).

## 5 Research design and methods

This chapter provides an overview of the methodological choices in Studies I, II, III and IV, together with an assessment of the studies' trustworthiness and ethical considerations. The current project has overall a qualitative exploratory design. When studying people's experience, this was a recognized and suitable design (Bradbury-Jones et al., 2009; Jakobsen & Sorlie, 2010; Lindseth & Norberg, 2004; Tuohy et al., 2013). Table 1 gives an overview of the studies in the dissertation.

Table 1: Overview of Studies I, II, III and IV

Study	Study I	Study II	Study III	Study IV
Aim	To synthesize research that investigated how patients and caregivers view spiritual care, come to understand the spiritual needs of people with dementia, and how caregivers provide care congruent with peoples' needs.	To investigate nurses and care workers' experience of spiritual needs in residents with dementia in nursing homes	To investigate how nurses and care workers carry out spiritual care for people with dementia in nursing homes	To investigate nurses' attitudes towards and accommodation of patients' expressions of religiosity and faith in dementia care in nursing homes
Design	Meta-synthesis	Qualitative explorative study	Qualitative explorative study	Qualitative explorative study
Methods	Synthesizing primary, empirical, qualitative studies	Focus-group interviews	Focus-group interviews	Focus-group interviews
Participants	Publishing study between 2009 and 2014	Nurses (RNs), care workers (LPNs)	Nurses (RNs), care workers (LPNs)	Nurses (RNs), care workers (LPNs)
Data collection	April–May 2014	June 2011–January 2012	June 2011–January 2012	June 2011–January 2012
Analysis	Meta-ethnography	Phenomenological–hermeneutic method for researching lived experiences	Phenomenological–hermeneutic method for researching lived experiences	Hermeneutic–phenomenological method for researching lived experiences

## 5.1 Meta-synthesis, Study I

The literature search that we initially conducted in this doctoral project in 2010 (thesis, pp. 16–17) showed that few empirical studies of spiritual care were conducted on dementia care in nursing homes that focused on nurses' perspectives of care. The methodological challenges of synthesizing findings from theoretical and empirical evidence, respectively, ensured that we wanted to resume a literature search at a later stage in the doctoral project, and to complete the literature review then, if possible. In retrospect, we could see that the literature search conducted in 2010 was too limited. We resumed the new and updated literature review in 2014.

Noblit and Hare (1988) state that meta-ethnography is concerned with the understanding of a phenomenon. Meta-ethnography is a useful method for synthesizing qualitative empirical research (Campbell et al., 2011; Noblit & Hare, 1988). It aims to interpret explanations from researchers' analysis of life ways, patterns or social events in the participants' lives in the primary empirical studies (Noblit & Hare, 1988, p. 11; Streubert & Carpenter, 2011). The method has proved to be widely cited in nursing (Britten et al., 2002; Campbell et al., 2011). Several primary qualitative study designs can be included, such as phenomenology, hermeneutics (naturalistic enquiry), grounded theory or ethnography (Noblit & Hare, 1988; Gough et al., 2012; Saini, 2012). Noblit and Hare (1988) distinguish between aggregative reviews in which different studies are pooled or aggregated, and inductive/interpretive reviews which bring together findings from different studies to gain deeper understanding of a particular phenomenon, as in Study I (Campbell et al., 2011; Noblit & Hare, 1988).

Study I is inspired by Noblit and Hare (1988, p. 26), who present seven phases in the implementation of meta-synthesis, for which it is emphasized that the phases overlap to some extent. The seven phases in the analysis are presented in Table 2.

Table 2: Noblit and Hare’s (1988) seven phases of conducting a meta-synthesis

Phase 1	Getting started. <i>Identify a topic of intellectual interest</i> . Defining the aim
Phase 2	<i>Deciding what is relevant to the initial interest</i> . Including relevant studies, describing search strategy, and criteria for inclusion and exclusion
Phase 3	<i>Reading studies</i> . Repeating reading of the studies noting their interpretative metaphors
Phase 4	<i>Determining the relationships between the studies</i> . Reading the findings of the primary studies and extracting metaphors, concepts, and themes and their potential relationships in the primary studies, which ends in an assumption of their relationship being reciprocal (findings across studies are comparable) or reputational (findings stand in opposition to each other) or represent a line of argument. ( <i>Second level analysis</i> )
Phase 5	<i>Translating the studies into each other (first level synthesis)</i> . Comparing metaphors and their interaction within single studies, and across studies, and at the same time protecting uniqueness and holism
Phase 6	<i>Synthesizing translations (second level synthesis)</i> . Creating a new whole from the sum of the parts
Phase 7	<i>Expressing the synthesis</i> . Finding the appropriate form for effective communication of the synthesis to the audience

Below is a description of the steps in the work with Study I, based on Noblit and Hare’s (1988) seven steps, as revealed in Table 2.

### 5.1.1 Identify a topic of intellectual interest (phase 1)

The current research field has been developing over time. We wanted to take advantage of this by searching for empirical studies that occurred while we were working on the doctoral project. We expanded the search from 2010 (thesis, pp. 16–17), which implicated that we did not limit searches to nursing home contexts, but also incorporated studies from home-based services and hospitals for people with dementia. With hindsight, we could have done this differently. In 2010, we excluded studies with patients’ perspectives, which we now wanted to incorporate. Furthermore, we did not limit the search to carers only, but more broadly to

healthcare professionals. The aim of the study was to synthesize research that investigated how patients and caregivers view spiritual care, come to understand the spiritual needs of people with dementia, and how caregivers provide care congruent with people's needs.

### **5.1.2 Deciding what is relevant to the initial interest (phase 2)**

*Data collection.* This meta-synthesis is interpretive and integrative. The following is a description of the steps in the search process and the selection of articles for Study I.

We conducted a literature search in March 2014, using the databases MEDLINE, Ovid Nursing, PsycINFO and CINAHL. The relevant MeSH-terms in MEDLINE, Ovid Nursing and PsycINFO were as follows: spiritual care, nursing care, nurse's practice, holistic nursing, pastoral care, dementia, dementia nursing, spirituality, spiritual, spiritual needs, religion and religious. The search terms in CINAHL were spiritual care in medicine, dementia and nursing home. We used the terms and searched using different combinations. The procedure for the selection of articles was inspired by the flow diagram from the PRISMA Group (Moher et al., 2009). The literature search led to the discovery of 395 articles. We also searched in key journals (e.g. *Dementia* and *Journal of Religion, Spirituality & Aging*). The following free text keywords were used: religiousness OR beliefs OR pastoral care AND spiritual care AND dementia care. The search resulted in the inclusion of 11 additional relevant articles. The flowchart for the literature search is described in Study I (see Appendix 1). We made an assessment of the remaining articles ( $n = 406$ ), based on abstracts, headings, subject matter in accordance with the inclusion criteria, and an assessment of the thematic relevance.

*Inclusion criteria.* The general inclusion criteria were that studies had to be primary empirical qualitative studies, peer-reviewed primary studies, published between January 2004 and March 2014, written in English, available with abstracts and based on the caregivers (nurses [RNs], healthcare professional/workers, family members) and patients' perspectives.

*Exclusion criteria.* Exclusion criteria implied that studies with outcomes such as quality of life, acute care, dialysis, loneliness, stroke, pain, restraints, depression ( $n = 289$ ) were excluded. All articles with a theoretical or quantitative design were excluded, as were book reviews and dissertations ( $n = 44$ ). Studies in a language other than English ( $n = 26$ ) were also excluded, as were any duplications ( $n = 9$ ). A new assessment of the remaining articles

( $n = 38$ ) was made; 23 studies were excluded because they were not specifically about spiritual needs and spiritual care in dementia nursing, and one because it was unobtainable; 14 studies were then assessed for eligibility, and 4 of these excluded due to divergent subject matter and/or lack of relevance.

*Quality criteria.* Quality appraisal of the included studies was based on Malterud's (2001, 2002) checklist. This checklist ensured a thorough review of the article's purpose, reflectivity, method, design, sample, theoretical framework, methodology, analysis, findings, discussion and conclusion. All the selected studies had acceptable methodological quality except for two which we excluded, based on the appraisal of the checklist. Eight studies were finally included in the qualitative synthesis.

### **5.1.3 Reading the studies (phase 3)**

*Characteristics of the studies included.* We considered the result sections of the primary studies as the outcome of a *first level analysis* (Dahl, Fylkesnes, Sorlie & Malterud, 2013). We formulated the following question as a starting point for analysis when reading the articles included: 'Which analytical concepts (metaphors) and themes are used to describe spiritual needs and spiritual care in dementia care?' All nine articles were read in the light of such descriptions.

The studies included were primary empirical studies published between 2009 and 2014. The studies were conducted in dementia care service/units, long-term care, nursing homes, home care or hospitals. The methods used varied across interviews, observations and reminiscence groups. The studies that we finally included in the meta-synthesis had a mix of different groups of informants. In four of the studies, the participants were residents/patients ( $n = 147$ ), (Beuscher & Grando, 2009; Dalby et al., 2012; MacKinlay & Trevitt, 2010; Welsh et al., 2012). In four of these there was a mix of participants, such as healthcare professionals ( $n = 30$ ), patients/residents ( $n = 39$ ) and their family members ( $n = 49$ ) (Bursell & Mayers, 2010; Carr et al., 2011; Gijssberts et al., 2013; Sullivan & Beard, 2014).

#### **5.1.4 Determine the relationships between the studies (phase 4)**

**Second level analysis.** The second level analysis constituted the first level synthesis of the eight articles in the sample (Dahl et al., 2013). The paper by Carr et al. (2011) was used as an index paper, and each subsequent paper entered into the synthesis was compared with it. We made a grid, in which reference to each study was listed horizontally, and the interpretive concepts/ metaphors, and themes outlined by the primary authors were listed vertically. The metaphors/concepts and/or themes in each account were compared with the metaphors, concepts and/or themes and their interactions in the other accounts (Gough et al., 2012; Tranvåg et al., 2013). This enabled us to understand how the empirical studies were related (reciprocal) and how (and if) they differed from each other (reputational) (Noblit & Hare, 1988; Whitemore & Knafl, 2005).

#### **5.1.5 Translating the studies into each other (phase 5)**

**First level synthesis.** We sought throughout the synthesis to be faithful to the original authors' perspectives in the primary studies to find the whole among a set of parts (phase 5; line of arguments). The first level synthesis resulted in the following three main headings describing spiritual care for people with dementia. (1) Performing religious rituals with patients that provide a sense of comfort and (2) coming to know the person, which provides opportunities to understand a person's meaning and purpose. (3) Attending to basic needs provides an opportunity to appreciate others' vulnerability and humanness, as described in the article of Study I.

#### **5.1.6 Synthesizing translations (phase 6)**

**Second level synthesis.** In the second level synthesis we discussed the findings from the first level synthesis. The reciprocal translations were subject to a process of reordering and reanalysis (Campbell et al., 2011; Noblit & Hare, 1988). In the second level synthesis, we discussed the first level synthesis in relation to research into the perspectives on 'meaning' of nursing and psychology of religion (Park, 2010). The synthesis resulted in a comprehensive description of spiritual care as revealed by 'expressing the synthesis' (phase 7).

### 5.1.7 Expressing the synthesis (phase 7)

**Comprehensive description.** This meta-synthesis has revealed three core areas that describe caregivers and patients' perspectives of spiritual care. First, spiritual care included helping people with dementia to express their faith and assist them in their need for a relationship with God/a deity. Second, it means meeting patients' need for meaning in life through recognizable and relevant activities, including those that might seem insignificant. The third point was that spiritual care means helping patients re-establish a connection with themselves and their sense of being, and, in turn, supporting and confirming them as valued individuals. The main understanding of spiritual care in dementia care seems to be the care for religiosity and faith, connectedness and meaning in life.

### 5.1.8 Trustworthiness

A challenge in qualitative research is that it is based on small samples that are not representative and, as the findings are context bound, they are difficult to synthesize (Saini, 2012; Sandelowski, 2008). Dependability refers to the stability of the data (Houghton, Casey, Shaw & Murphy, 2013). Sandelowski (2006, 2008) refers to several challenges when it comes to integration of qualitative research. One challenge is that few rules guide qualitative analysis, which may lead to inconsistencies in terminology describing the implementation of qualitative research (Saini, 2012; Sandelowski, 2008). Different primary studies are based on different disciplines, philosophical assumptions, theoretical frameworks and political ideologies, which can create tension when it comes to questions about epistemology and ontology during integration of the findings (Saini, 2012). This means that one must be aware not only of the methodological similarities in the study being included, but also of the quality of the various studies. We were aware of this during the selection of articles for the synthesis, and two people discussed and selected the sample and made decisions (Liv S. Ødbehr [LSØ] and Kari Kvigne [KK]). Credibility refers to the believability of the findings (Houghton et al., 2013). Thorne (2008) states that it must be consistent between the research question and the interpretation of data sources and interpretive strategies used. We documented every step in the analysis in as much detail as possible. The transparency of the studies included could increase the quality of the synthesis and, in turn, assist the possibility of the findings' transferability (Saini, 2012). 'The consistency relates to the degree to which the conclusions follows logically from the research processes and analytic steps' (Paterson, Thorne, Canam &

Jillings, 2001, p. 52). We chose to be open and explained in detail the steps and choices during the analysis (shown in Study I), by reflecting on our own pre-understanding and the tension between the wish to produce rich and substantive accounts, on the one hand, and how to deal with the preconditions and consequences of the research given, on the other (Malterud, 2001). The conformability was safeguarded by use of quotes in the findings' presentation from the primary studies included in the sample. This was a way of identifying with participants' stories in the primary studies, and understanding the underlying thinking in the findings that we sought to synthesize (Saini, 2012).

## **5.2 Empirical Studies II, III and IV**

In the following is a presentation of the method used in the empirical Studies II, III and IV. A description of the ethical considerations that followed the empirical studies is provided. The Consolidated Criteria for Reporting Qualitative Research (COREQ) – a 32-item checklist for interviews and focus groups – was used during the work on these studies (Tong et al., 2007). The chapter ends with an assessment of the trustworthiness of the studies.

### **5.2.1 Setting and context**

The nursing homes in the current project were located in southern Norway. We contacted the leader for nursing and care services in three different municipalities initially via email and letters with a request to participate in the study. Four nursing homes (A, B, C, D) were invited and accepted participation in the study. After the positive response, we contacted the institutional leaders at the four nursing homes by email. We met the management team at each institution and provided information about the study orally and in writing to the leaders of the different wards in the nursing homes. The information included aims, participants, methods, analysis and plans for publication of the results. We decided to put a time and duration for the initial interviews. I also asked for the opportunity to return later and conduct a follow-up interview. The proportion of nurses, from the total of all employees in the nursing homes, varied. In nursing home A, 23% of the employees were registered nurses (RNs), in nursing home B 23% were RNs, in nursing home C 27% were RNs, and in nursing home D 42% were RNs, as shown in Table 3.

Table 3: Nursing homes, main characteristics

<b>Nursing homes</b>	<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>
<b>Employees: <i>n</i></b>	216	207	74	70
<b>Departments: <i>n</i></b>	4	5	4	3
<b>Nurses (RNs): <i>n</i></b>	51	48	20	30
<b>Care workers: <i>n</i></b>	129	68	32	40
<b>Assistants/other: <i>n</i></b>	36	91	22	43
<b>Residents: <i>n</i></b>	103	116	29	54

The figures in the table indicate the size of the different nursing homes. Residents are not included in the study.

## 5.2.2 Recruitment and participants

The leader of each ‘department’ of the nursing home recruited the participants for the interview study, in line with purposive sampling. Two employees were asked to voluntarily participate. Recommendations for the appropriate or useful number of participants in focus groups are between four and twelve (Morgan, 1997). We considered eight participants suitable because we would be able to withstand any of the participants withdrawing from the study. Inclusion criteria were:

- Four nurses (RNs) and four care workers (licensed practical nurses [LPNs], auxiliary nurses, health workers, assistant nurses) at each nursing home, two employees in each ‘department’ of the nursing homes.
- Employees with an interest in the subject.
- Participants with a minimum of 1 year’s work experience.
- Both men and women were required in each focus group.

The rationale for including both care workers and RNs in the sample is that fewer RNs participate in caring situations in nursing homes than care workers because most RNs have expanded administrative responsibilities and offer less time for patient care. We did not compare the occupational groups, because of the consideration that the participants jointly created data in each focus group. Participants (RNs and LPNs, auxiliary nurses, health

workers, assistant nurses) are thus referred to as ‘nurses’ in Studies II, III and IV. A total of 31 RNs and care workers participated – 1 man and 30 women. Of the participants 16 were RNs and 15 care workers; 4 of the participants had further training in geriatrics (RN = 1) and palliative care (RN = 1, care workers = 2). Of the participants 17 had worked more than 10 years in dementia care and had a lot of experience of working with people with dementia. Of the participants, 16 were aged over 50 years and 17 had worked more than 10 years in dementia care. The oldest participant was aged 70 years. The participants’ age and working experience are shown in Table 4.

Table 4: Participants’ age and work experience

<b>Age (years)</b>	<b><i>n</i></b>	<b>Working experience (years)</b>	<b><i>n</i></b>
<b>&lt;30</b>	4	<b>&lt;5</b>	4
<b>30–50</b>	11	<b>5–10</b>	10
<b>&gt;50</b>	16	<b>&gt;10</b>	17

### 5.2.3 Data collection

We conducted eight focus-group interviews, with two at each nursing home: (1) interview 1 and (2) follow-up interview. An advantage of focus groups is that they are useful for exploring sensitive issues, because it could be easier to talk about such issues together with others (Kitzinger, 1994, 1995; Krueger, 1998; Malterud, 2012; Morgan, 1998). Furthermore, focus groups are well suited to exploring attitudes and subjective experiences among participants, and the depth and complexity of a phenomenon (Carlsen & Glenton, 2011). This was the reason why we chose focus groups rather than individual interviews.

It is a criticism in nursing research that phenomenology and focus groups are methodologically incompatible (Bradbury-Jones et al., 2009; Webb & Kevern, 2001). Webb and Kevern (2001) criticize phenomenology in focus-group investigations by highlighting the fact that the essence of an individual person’s experience disappears in a group discussion. Each person’s subjective experience is rather turned into the group’s overall experience. Bradbury-Jones et al. (2009) argue that focus groups are nevertheless congruent with a phenomenological method. This project is grounded in interpretative phenomenology, which

concerns the ‘meaning’ of the text. Interpretive phenomenology is in some research referred to as ‘hermeneutics’ (Touhy et al., 2013), which means that humans are already embedded in a world of meaning (van Manen, 1997b). The dialogue and collaboration are a part of the phenomenological endeavour.

The facilitator (LSØ) and the moderator (KK) conducted the focus-group interviews. Each interview lasted 1.5–2 hours (90–120 minutes). The participants received a thematic guide with a main question and four subordinate questions in advance. The initial question was “Is spiritual care a familiar term in care for people with dementia?” Subordinate questions were:

- How do you understand spiritual care?
- How do patients express spiritual needs?
- What knowledge among nurses is important when conducting spiritual care in practice?
- Why do you think spiritual care is important in dementia care?

The number of participants who attended each focus-group interview was between four and eight (Morgan & Scannell, 1998). Table 5 gives an overview of the participants in interview 1 and the follow-up interview.

Table 5: Participants in interview 1 and the follow- up interview

<b>Nursing home</b>	<b>Interview 1</b>	<b>Follow-up interview</b>	<b>New participants in the follow-up interview</b>
<b>A: n</b>	6	4	2
<b>B: n</b>	8	6	0
<b>C: n</b>	6	6	3
<b>D: n</b>	6	4	0
<b>Total: n</b>	26	20	5

The follow-up interview was held at each nursing home after 8–12 weeks. Follow-up interviews were characterized by elaboration and discussion of the themes from the first interview. Hummelvoll (2008) denotes that ‘multistage focus groups are characterized by the group exploring a certain theme through several meetings’ (p. 5). By several meetings, Hummelvoll means re-interviewing three times in each focus group (multistage). Hummelvoll

and Severinsson (2005) state that re-interviewing participants in focus groups implies that the knowledge dialogue contributes to an increasingly deeper investigation of the theme. We were inspired by Hummelvoll and Severinsson's (2005) method of multistage interview when implementing our empirical study, although we did not complete three focus-group interviews at each nursing home, only two. In line with the work of Hummelvoll (2008), new participants may stimulate the group dynamics and vitalize the enquiry in that the group, cooperating in a new way through the addition of more detailed conversations on the topic (Hummelvoll, 2008). Although there were five new participants in the follow-up interview (two participants in nursing home A and three in nursing home C), continuity was maintained throughout because someone from the first interview was always present in the follow-up interview (Hummelvoll, 2008). Research reveals that studies report saturation after two to thirteen focus-group interviews (Carlsen & Glenton, 2011). We experienced saturation after eight interviews with no new themes emerging.

Memos and summaries during the interviews were written, and the interviews were recorded as audio files (Morgan, 1997; Patton, 2002; Silverman, 2004; Webb & Kevern, 2001). The moderator wrote notes during the group conversation as associations, themes that needed more investigation and observations of interactions between group participants during the interview. The facilitator wrote down her own impressions right after the interview finished, together with a comprehensive summary from each interview, and initially presented a summary to the participants in the follow-up interview. The aim was to get feedback and supplementary comments to the summary from the participants. The facilitator transcribed each audio file verbatim.

Homogeneity may cause participants in the focus group to recognize and identify each other's experiences, which increases the associative effect (Malterud, 2012; Morgan, 1997). Participants from the same context may understand each other's daily life conditions in the 'department' and therefore have a larger repertoire of shared experiences than when facing participants from quite different contexts (Kitzinger, 1994, 1995). The homogeneity in the focus groups was addressed by having participants from similar contexts, a predominance of women among participants, even if unintended, and only two occupational groups being represented in the focus groups (e.g. nurses and care workers). At the same time, *variation* could contribute to disclosure of a range of different perspectives and views in relation to the themes discussed. Participants in focus groups do not necessarily need to know each other in

advance (Morgan, 1997). Variety may explore the diversity of the participants' experiences and contribute to nuances in the empirical data (Malterud, 2012). The participants in the focus groups came from different departments, which helped to establish some variance in them. The dialogues in the focus groups were open and reflective. The facilitator asked participants directly if they appeared to be inactive. Participants dealt with the problem of the content of spirituality and religiosity, exploring the meaning of the terms. We allowed there to be silence in the groups (Barbour, 2007; van Manen, 1997b).

#### **5.2.4 Data analysis**

Data analysis of the interview text in Studies II and III was conducted according to Lindseth and Nordberg's (2004) phenomenological–hermeneutic analysis. In the following is a presentation of the data analysis for these two studies together. Data analysis in Study IV was completed using van Manen's (1997a, 1997b) hermeneutic–phenomenological method of interpretation, and so is presented independently thereafter.

#### **Studies II and III: phenomenological–hermeneutic method of interpretation**

Phenomenological–hermeneutic methodology was applied in the analysis, inspired by Lindseth and Nordberg's (2004) analysis of the text. The method was suitable for investigating lived experiences in which we drew on a shared awareness in the nurses' working life world where spiritual care took place (Lindseth & Norberg, 2004). The use of notes to support the interview analysis was made in both the naïve reading and the structural analysis. The structural analysis made it possible to uncover the nurses' experiences that they shared in the focus-group interviews, so the research methods had to be hermeneutic, e.g. a method based on interpretation (Lindseth & Norberg, 2004). Furthermore, we wanted to present the findings in a format as close to that of the informants as possible (Willig, 2011). Details of the steps in the analysis are described in Studies II and III, and structured according to the steps (Lindseth & Norberg, 2004) summarized below.

## **Naïve reading**

By naïve reading is meant reading the text several times to grasp its meaning as a whole. The reader can be touched by the text, and writes down spontaneous impressions during its reading. Naïve understanding guides the structural analysis in that it validates or invalidates the structural analysis (Lindseth & Nordberg, 2004).

## **Structural analysis**

Structural analysis is the methodical instance of interpretation, i.e. a way of seeking to identify and formulate themes by formulating units of meaning, condensed units of meaning (i.e. the essential meaning of each unit of meaning, expressed in everyday words), subthemes, themes and formulation of the main themes. The themes are reflected in relation to naïve understanding. When there is discrepancy between naïve reading and the themes in the structural analysis, the whole text is read again, and a new naïve understanding formulated and checked by a new structural analysis. This process continues until the naïve understanding of the structural analysis is consistent (Lindseth & Norberg, 2004).

## **Comprehensive understanding**

Comprehensive understanding means that the main themes, themes and subthemes are summarized and reflected on in relation to the research question, and the context of the study. The whole text is read again with naïve understanding, and with the validated themes in mind, and with an open mind. Through critical reflection, the reader can revise, broaden and deepen his or her own awareness of the text's meaning. Discourse with other people and/or texts may help the reader to become aware of his or her pre-understanding, e.g. phenomena that people take for granted, such as phenomena related to culture and the person's history (Lindseth & Norberg, 2004).

The whole process involving naïve reading, structural analysis and formulation of comprehensive understanding made us work in line with the hermeneutic circle in the data analysis. The analysis method was thorough and helped to dwell on certain themes to find similarities, differences and nuances in the descriptions of spiritual care in the interview text.

#### **Study IV: hermeneutic–phenomenological method of interpretation**

During the work with the data from the focus-group interviews, we saw that the nurses were struggling with some issues related to religious care. We found participants' experiences interesting and vital in terms of exploring the hindrances to providing spiritual care in practice. These hurdles created tensions among nurses and ensured that they went back and fourth between different alternatives in the face of a patient's needs. The nurses could to an extent describe spiritual care, but found that religious care had several forms of restraint. We therefore wanted to focus on religious care in relation to nurses' attitudes and the way in which they dealt with patients' religious expressions.

Interpretative phenomenology is useful when interpreting human experiences (Wojnar & Swanson, 2007). In Study IV, we were inspired by van Manen's (1997b) hermeneutic–phenomenological method of analysis. Descriptions of the steps in the analysis are provided in Study IV. Phenomenological themes may be understood as the structures of experiences, in line with van Manen (1997b). Investigations of human perspectives and experience are an appropriate source for uncovering aspects of a certain phenomenon, and furthermore discover the meaning of the phenomenon. We went back to read the whole text, and van Manen's (1997b, p. 30) conditions in the analysis were applied as in the following:

- To investigate experiences as they are lived rather than as they are conceptualized
- To reflect on the essential themes that characterize the phenomenon
- To describe the phenomenon through the art of writing and rewriting
- To maintain a strong and oriented pedagogic relationship to the phenomenon
- To balance the research context by considering the parts and the whole.

The hermeneutic version of phenomenology means that the interpretation brought by the researcher to the text constitutes an integral part of phenomenological analysis (Willig, 2013). In this tradition of interpretative phenomenology, the description and interpretation are not separate, but rather give insight from the hermeneutic tradition and argue that all descriptions constitute a form of interpretation (Willig, 2013).

## 5.2.5 Trustworthiness

Trustworthiness of qualitative research parallels the standard of reliability and validity in quantitative research (Denzin & Lincoln, 2011; Lincoln & Guba, 1985). Lincoln and Guba (1985) suggested five criteria for developing the trustworthiness of a qualitative enquiry: credibility (truth, values, replaces internal validity), dependability (consistency, replaces reliability), conformability (neutrality, replaces objectivity), transferability (applicability, replaces external validity) and authenticity. The following is an exploration of the perspectives mentioned.

**Credibility** refers to the overriding goal of qualitative research. Credibility is an important aspect of trustworthiness; it is achieved when the research methods engender confidence in the truth of the data and in the researchers' interpretation of the data (Polit & Beck, 2008). To ensure credibility, all researchers in the research group (LSØ, KK, Solveig Hauge [SH] and Lars Danbolt [LD]) worked with the analysis. Equivalence and internal consistency were maintained by the same facilitator and moderator conducting all the interviews, and the facilitator transcribing all the interviews (Streubert & Carpenter, 2011; Tong et al., 2007). Joint reflection in the focus groups contributed to the elaboration of certain themes, by which topics from interview 1 were emphasized in the follow-up interview. In the research group, we therefore discussed the interpretation of components of meaning (themes and subthemes) in the analysis. We maintained an audit trail via notes and documentation of decisions, assumptions, drafts and conclusions during work on the studies (Cope, 2014). A form of 'member checking' was achieved through findings from the studies being presented to some of the participants in seminars to obtain feedback on conclusions and findings (Cope, 2014).

**Dependability:** the dependability of a group is affected by the stability, which over time depends on the participants. Although there were new members in the follow-up interview, several attendants at the first interview maintained stability in the follow-up interview (Streubert & Carpenter, 2011). We documented every step during data collection and data analysis. In each of the Studies II, III and IV we offered information about the setting, participants and analysis process, providing as detailed and comprehensive a picture as possible. The use of quotes and examples in the articles helped to support the dependability as well as the transparency of the research process. Patricia Munhall (2012) emphasizes that the findings must represent the presentation of the lived experience examined by the multiple data

sources. Munhall (2012) furthermore points to relevance of the findings increasing readers' consciousness, giving a sense of increased understanding of the meaning of the phenomenon under investigation. Here, Munhall (2012) used the word 'resonance', in the sense that the interpretation of the meaning of the experience is sound and reasonable.

**Confirmability** (neutrality) refers to findings needing to reflect the participants' voices (Polit & Beck, 2008), and to data that are not fragmented by the enquirer's imagination. In the work with the interview text, we read and re-read the interview text several times to be able to grasp the text meanings and to challenge our pre-understandings and early conceptualizations. We wanted to be close to the text, but at the same time have an outside perspective when reading the text. The method that was used in Studies II, III and IV was discussed regularly with other researchers. The empirical study has been presented to laypeople and other interested parties several times. On the way, we have received input and views about various aspects of the study, which has helped to shape, change and strengthen the work of the papers during the process. Confirmability was also sought to safeguard the consistency of the themes and quotes in the study context. We were constantly aware of the risk of researcher bias and discussed each step in the research group.

**Transferability (applicability)** refers to what extent the qualitative findings can be transferred to other settings or groups (Polit & Beck, 2008). We enhanced the transferability of findings through creative reflective journals and detailed descriptions. The sample size in this study was small, but we think that the findings may be recognizable in other similar settings in Nordic contexts, in that the themes and setting can be recognized by practitioners (Polit & Beck, 2008). Insofar as findings are recognizable in other contexts, it might also be considered relevant there.

**Authenticity:** the authenticity of the studies refers to the extent to which the researcher faithfully shows a range of different realities in the findings' presentation and the way in which the participants' feelings and emotions are expressed faithfully by the researchers (Polit & Beck, 2008). We sought to identify participants' experiences and perspectives in a varied and detailed way through the use of quotes.

## 5.2.6 Ethical approval

Ethical approval was obtained from Norwegian Social Science Data Services (NSD) in the form of a confirmation of notification of the processing of personal data. The project was approved for research on 18 April 2011, with reference no. 26783. The study was based on the World Medical Association's (WMA's) Declaration of Helsinki statements of ethical principles for medical research involving humans (64th WMA General Assembly, Fortaleza, Brazil, October 2013). We emphasized that data were treated confidentiality to safeguard and protect the informant's integrity, privacy and identity. A written informed consent was accompanied by emphasis that the participation was freely and voluntarily given, and that the participants could withdraw from the study at any time during the data collection without reprisal. It was also emphasized that presentation of the results of the studies would be anonymized.

We received permission in advance to conduct the study from the care managers in the relevant municipalities and institutional leaders at the nursing homes. The nurses in this project were not asked directly about their personal faith and religious standpoint. Recent statistics in Norway (SSB, 2013) show that 82% of the Norwegian population were members of the Church of Norway (Lutheran) [DNK] in 2009. In 2012, 76% of the Norwegian population were members of the DNK out of a population of 5 million people (SSB, 2013). Personal faith and beliefs are sensitive information, and could be an obstacle to further group conversations because in Norwegian culture such questions are considered to be a private matter (Botvar & Schmidt, 2010), but also because this was not the focus in the project. We did not want to compare questions on various religious issues or access the importance and relevance of religiosity among the participants.

## 6 Main findings

This chapter provides a description of the main findings in the dissertation of Studies I, II, III and IV.

### 6.1 Study I: patients' and caregivers' views on spiritual care and their understanding of spiritual needs in persons with dementia; a meta-synthesis

**The aim of the study** was to synthesize research that investigated how patients and caregivers view spiritual care, come to understand the spiritual needs of people with dementia and how caregivers provide care congruent with peoples' needs.

The meta-synthesis incorporated the patients' perspectives, in that several of the studies based their data on patient information as well as information from family members. Few studies had an unambiguous nursing perspective in their sample. The studies included in this meta-synthesis presented different views in relation to spiritual needs and spiritual care. The differences may nevertheless have contributed to a more complete picture of the topic studied. We described the first level synthesis of the primary studies as three main themes: (1) performing religious rituals with patients provides a sense of comfort, (2) coming to know the person provides an opportunity to understand the person's meaning and purpose, and (3) attending to basic needs provides an opportunity to appreciate another person's vulnerability and humanness.

#### **Performing religious rituals with patients to provide a sense of comfort**

Both patients and caregivers described spiritual care as taking care of patients' religiosity: facilitating the patients' need for expression of religious faith, their relationship with God and religious identity, and facilitating religious practice such as prayers, readings and attending church. The findings also revealed that spiritual care encompassed the promotion of people's values, including hope for the future. The importance of hope was emphasized despite the progress of dementia in patients' lives, and it was revealed as a force during times of great loss.

### **Coming to know the person to provide the opportunity to understand a person's meaning and purpose**

The healthcare professionals saw their job as helping patients maintain the relationships with themselves and others, which kept a sense of connectedness in their life. The relational aspect was highlighted because many patients to some extent experienced loneliness and isolation from social relationships. In addition the healthcare professionals emphasized the need to strengthen patients' integrity and preservation of the 'self' which, in turn, could promote personhood and the feelings of being valued as a human being.

### **Attending to basic needs to provide an opportunity to appreciate the vulnerability and humanness of others**

Spiritual care was described by healthcare professionals as the ability to engage patients in familiar activities that could provide a sense of meaning, contribute to life and furthermore help the patient become engaged in spiritual reminiscence as a way of meaning making. This was achieved through doing little things in everyday life such as attending to the basic needs in patients' lives.

**Expressing the synthesis:** this meta-synthesis revealed that spiritual care included helping people with dementia to express their faith and assisting them in their need for a relationship with God/a deity. The healthcare professionals emphasized that patients needed to re-establish a connection with themselves and their sense of being. Both healthcare professionals and patients felt that supporting and confirming patients as valued people was important. The healthcare professionals found that patients needed to experience meaning in life, and one way to achieve this was to engage them in meaningful activities. This study shows that it is still relevant even in advanced dementia.

## **6.2 Study II: nurses' and care workers' experiences of spiritual needs in residents with dementia in nursing homes; a qualitative study**

**The aim of the study** was to investigate nurses and care workers' experiences of spiritual needs in residents with dementia in nursing homes. We described the findings in this study in

three main themes: (1) the need for serenity and inner peace, (2) the need for confirmation, and (3) the need to express faith and beliefs.

### **The need for serenity and inner peace**

The study revealed that the patients needed a place where they could experience serenity and inner peace. Such moments were described as ‘good moments’. Music and physical massage were a useful way to make patients relax and achieve contemplative and restful moments. Music could, furthermore, evoke both good and bad emotional reactions for the patients. Familiar activities were also a way to help patients calm down from being restless and agitated, because such activities helped the patients cope with everyday life situations. Activities were considered a way of promoting a sense of meaning in patients’ lives.

### **The need for confirmation**

The nurses experienced that patients needed a form of confirmation about who they were as people. This was described as a way of meeting a patient’s need to feel valued as human beings; furthermore it was a way to be remembered as the person he or she once was before the onset of dementia. The nurses experienced that patients needed to have a form of acceptance and acknowledgement of their identity; this strengthened patients’ experience of self-worth – in other words the patients needed to feel loved. Nurses believed that patients could experience love in relationships which helped to strengthen patients’ sense of personhood. This could be achieved in situations where nurses could establish an atmosphere of tenderness, and when they met patients’ need for a hug and closeness through holding hands, or just being near the patients. The social interaction helped to confirm the patient’s wholeness as a person.

### **The need to express faith and beliefs**

The nurses saw that patients needed to express faith and beliefs. They observed that many patients expressed a need to participate in worship and prayers, to listen to hymns or to implement religious activities during everyday life, or to talk about difficult subjects such as death approaching, or the fear of being alone.

**The conclusion** in the study was that nurses found that patients needed to experience meaning in life, intrapersonally, interpersonally and transpersonally. Nevertheless, the study

revealed a need to develop more knowledge of how people with dementia express spiritual needs and what kind of spiritual needs are most prominent in these people.

### **6.3 Study III: spiritual care within dementia care: focus-group interviews of how nurses and care workers carry out spiritual care in nursing homes**

**The aim of the study** was to investigate how nurses and care workers carry out spiritual care for people with dementia in nursing homes.

We described the findings in this study through three main themes: (1) integration of spiritual care into general care, (2) spiritual care in terms of togetherness and (3) spiritual care providing meaningful activities for everyday life.

#### **Integration of spiritual care into general care**

Nurses described spiritual care as being integrated into general care. Spiritual care was associated with preserving patients' dignity, stroking their cheek when meeting patients' eyes or sitting at patients' beds. These care actions were described as 'working with hands and heart'. Furthermore, the nurses understood spiritual care as something inherent in tacit knowledge, described as intuition providing greater sensitivity for the patients. Intuition depended on the nurses' ability to listen to the patients, observe them and meet their longings. The nurses described spiritual care as being grounded in attitudes such as the wish not to harm, but to do the best for patients.

#### **Spiritual care in terms of togetherness**

Spiritual care was also perceived as a form of togetherness in relationships, by which nurses felt it would lead to patients experiencing security and feelings of being understood and valued. The nurses put an emphasis on expressing empathy and reciprocity and/or, if necessary, to be still in order to create a conflict-free interaction with patients. Furthermore, it involved producing a happy mood in patients' lives through use of small talk by the nurses, and showing genuine interest in and acceptance of the patients. The nurses described this as a form of connection between themselves and the patients; they wanted to help the patients connect to the environment as well as to other people in their surrounding.

### **Spiritual care providing meaningful activities for everyday life**

Nurses emphasized that giving spiritual care was about their ability to lead the patients to certain activities that created engagement, where the patients could use different senses. By use of senses is meant facilitating activities such as smelling, tasting, eating or going for a walk, or activities such as prayers, going to church, reading the Bible or talking about the symbols in patients' rooms.

**The conclusion** in the study was that the nurses understood that they had limited knowledge about spiritual care in dementia nursing. Through the focus-group interviews, they admitted that spiritual care was part of their daily practice, carried out through intuition, and it was more common than they realized. Furthermore, spiritual care was expressed in relationships between nurses and patients, characterized by reciprocity and empathy.

## **6.4 Study IV: a qualitative study of nurses' attitudes towards and accommodation of patients' expressions of religiosity and faith in dementia care**

**The aim of the study** was to investigate nurses' attitudes towards and accommodation of patients' expressions of religiosity and faith in dementia care in nursing homes. We described the findings in this study under three main themes: (1) embarrassment versus comfort, (2) unknown religious practice versus known religious practice and (3) life versus death.

### **Embarrassment versus comfort**

The first theme was the nurses' feelings of embarrassment when the patients wanted to sing religious songs in the 'home' and they had to join in the singing. The dilemma was that nurses considered religious faith to be a private matter, so they were unsure whether meeting such needs was their responsibility. An additional dilemma was the extent to which patients themselves understood their own religious needs as a real need. The nurses expressed patients' religious faith being primarily a private aspect of their lives. In addition, they felt that they had little knowledge of religious traditions, so they distanced themselves from patients' religious beliefs.

### **Unknown religious practice versus known religious practice**

Another dilemma was linked to religious practice that was unknown as against known by the nurses, an example being when one of the patients spoke in tongues. Patients' religious practices could sometimes be experienced as scary, and nurses did not always know how to accommodate and handle such situations. This resulted in the nurses trying to lead the patients on a path that was familiar to the nurses, even though they had to interrupt patients' religious expressions. The nurses experienced this as unsatisfactory. In turn, this practice created a sense of inadequacy and the nurses felt that they needed help from a priest or other religious leader.

### **Death versus life**

The last point from this work was that the nurses saw patients expressing a need to talk about death as a way of summarizing and ending life. The nurses, however, wanted to protect patients from dealing with subjects and experiences that could make them depressed. They therefore attempted to steer the conversation to something more positive such as dealing with everyday events or joyful subjects. In this way, the nurses avoided meeting patients' religious needs.

**The conclusion** in the study was that nurses felt that they lacked knowledge about the significance of religiosity and faith in patients' lives. The nurses struggled with ambivalent feelings because they were uncertain how to understand religious expressions in patients' lives and how to respond to them properly. On several occasions these challenges occurred in person-centred care and holistic care.

## **6.5 Comprehensive understanding**

The overall findings in this dissertation reveal that nurses' experiences of patients' spiritual needs were described as patients needing to experience a connectedness to self, other people and God/a deity. Nurses attempted to establish good relationships with the patients to achieve outcomes such as increased cognitive activation, emotional stimulation and social participation for most of their patients with dementia. The findings showed that a main motive for nurses was to prevent meaninglessness in patients' lives and promote 'meaning'.

Furthermore, the findings revealed that some patients needed to talk about death as a way of processing and finishing their life, but did not get the opportunity. In addition, this project has revealed that there were several challenges in nurses' lives of a personal, cultural and collective character, which prevented their provision of spiritual and religious care. Throughout the project, the descriptions of spiritual care were identified as part of holistic care in that it permeated all other forms of care. The nurses described spiritual care in practice in terms of person-centred work, and yet they acknowledged the difficulty in achieving this.

# 7 Discussion

The main purpose of this doctoral thesis is to explore how nurses RN's and care workers carry out spiritual care in nursing homes, by focusing on their experiences and perspectives of the spiritual needs of people with dementia. The discussion of the findings in Studies I, II, III and IV are divided into two main headings, (1) spiritual needs, experiences and perspectives, and (2) how nurses' carry out spiritual care.

## 7.1 Spiritual needs, experiences and perspectives

The findings in empirical Studies I and II of this dissertation revealed that patients lost their feelings of connectedness to self and to important values as the dementia progressed. The nurses (Study II) saw that patients struggled with low self-esteem and needed to get confirmation in relation to their personality. Furthermore, the nurses meant that their attitudes towards the patients had to be based on love and respect as a way of preserving a patient's need for connectedness to self (Studies I and II).

Nurses' experiences of patients' spirituality and spiritual needs is on the whole in line with Reed's (1992) description of spirituality as an experience of connectedness to self 'intra-personally', although the nurses (Study II) felt that they had few words to describe this. In addition, nurses (Study II) focused mainly on patients' loss of self-perception. The sociologist Lars Tornstam (1997) states that human ageing normally implies a shift in metaperspective from a materialistic world view to a transcendent one, which led to increasing satisfaction with life. Tornstam (1997) calls this changing process 'gerotranscendence', which means a change in and development of the self (Tornstam, 1997; Wadensten, 2005). The change itself is described as human experience of a higher state of maturity, a shift from egoism to altruism and decreased self-centredness (Tornstam, 1997; Wadensten, 2005). This was quite the opposite of what the nurses in our empirical studies experienced (Study II), because the nurses to a large extent focused on patients' experience of connectedness to self. One question is whether the nurses believed that the development of dementia impeded patients' gerotranscendence, and therefore they needed to focus on patients' perceptions of themselves. A major challenge in the lives of people with dementia is that their consciousness of their identity gradually changes, which affects their sense of 'being in the world' (Kitwood, 1997,

1998). People with dementia tend to have an impaired experience of self-awareness and self-perception due to the cognitive deficits, and they often forget whom they were previously (Kitwood & Johnsen, 1999). Nurses (Study II) felt that they lacked clarity in their understanding of spirituality. Furthermore, they experienced that it was challenging to help patients with dementia connect to their 'self', because patients' experiences of 'self' seemed to be fragmented, and many of the patients no longer remembered their own life histories.

Nurses in the empirical studies (Study II) experienced patients with dementia as being restless and without peace, and struggling to achieve mental calmness. The nurses wanted to meet the patients' need for serenity and described this as a 'good moment' (Study II). Haugan et al. (2012) confirmed these findings in a study by claiming that self-transcendence experienced intrapersonally had an impact on patients' experiences of subjective, emotional and social well-being. As revealed in Study II, the nurses did not use the word self-transcendence, but the description of a 'good moment' is in line with spirituality as an experience of something 'exceeding' normal experience for a brief period of time (Pargament et al., 2014). Good moments may also be associated with something boundless, such as the experiences of self-transcendence in line with Reed (1992). Yet the boundlessness in the lives of patients with dementias is difficult to evaluate, due to limitations in their communication ability. One question is how the nurses discerned between patients' experience of peace from physical rest and calmness, and that of peace from inward serenity and wellness. The questions reveals the complexity of spiritual care within dementia care and partly explains why nurses experience patients' spirituality as challenging.

The findings in this dissertation refer to some patients expressing the need for a relationship with God/a deity (Studies I, II, III and IV). Nurses (Studies I and II) experienced some the patients coping with religious activities as the dementia progressed. Religious activities such as prayers could evoke memories and stimulate behaviour and skills in patients' lives. Research shows that spirituality and religiosity are significant in many people's lives as they increased well-being and life satisfaction (Thege et al., 2013; Aldwin et al., 2014). In a systematic evidence-based review of Bonelli and Koenig (2013), the authors found that religious involvement correlated with better mental health in the lives of those with dementia and other stress-related or mental disorders. They concluded that religious involvement had a positive effect on depression. However, in spite of the evidence, some nurses (Studies II and IV) questioned whether religious activities were relevant in the daily lives of patients with

dementia, especially as they did not ask about them spontaneously. The same findings were evident in Study IV, where the nurses did not have clear understanding of the significance of religiosity in patients' lives. From this, the nurses had a limited focus on the content of patients' faith or religious history. Schnell (2011) states that meaningfulness is associated with a person's appraisal of life as 'directed'. The nurses in this dissertation did not use such terms in their discussions of patients' needs for help with regard to caretaking religiosity, faith and core values in life.

The nurses in the current empirical studies expressed a wide understanding of spirituality and that spirituality was an overarching religiosity. It appears that nurses favour spiritual needs, but have less focus on the religious needs of patients. Some researchers argue that the hardest thing is the polarization between religion and spirituality where religiosity is considered as static, institutional, objective and faith based, and spirituality is considered as dynamic, personal, subjective and experientially based (Zinnbauer & Pargament, 2005). We found tendencies of such a polarization, especially in Study IV.

## **7.2 How nurses carry out spiritual care**

The discussion of how nurses implemented spiritual care is organized under the headings: (1) particular religious spiritual care and (2) general spiritual care.

### **7.2.1 Particular religious spiritual care**

Only a few nurses in the current empirical studies (Studies III and IV) facilitated patients' religious activities in the nursing homes, although most of the nurses in the interviews felt that it was important for patients to express religious beliefs. Nurses helped patients to devotions, to listen to Church services on the radio or to read a devotional book, but the nurses felt sometimes that this was insufficient for the patients.

Pargament (1997) highlights that religiosity is a 'search for significance in ways related to the sacred' (p. 32). A relevant question is whether the nurses who participated in the empirical studies avoided religious care for patients with dementia because they were not familiar with the sacred. Few nurses (Study IV) felt that patients' relationship with God appeared to be

sacred in their lives, and that they perceived the sacred dimension as important. Nurses (Study IV) talked of a patient speaking in tongues, which was significant for the patient, but which they interrupted. The nurses felt that patients might be unable to talk extensively about the sacred or experiences of God. Nevertheless, the nurses (Studies III and IV) saw that patients showed signs of happiness after attending devotionals, or signs of harmony for a short while. An additional question is whether nurses did not safeguard the sacred because they did not know how to care for it. Nursing research describing spiritual needs elaborates on the sacred to only a limited extent (Koenig, 2008). The nurses admitted that the sacred could be important in patients' lives, but they did not know how to relate to this side of spiritual care. Religiosity as a search for the sacred was not elaborated on, although the sacred is a vital part of the understanding of spirituality in research (Pargament et al., 2014). Another way to understand nurses' lack of competence is that Pargament et al.'s (2014) abstract concepts may seem to be alienating and difficult for nurses to put into practice.

Nurses' experiences of patients' religious activities were unfamiliar to them (Study IV), because they did not share patients' religious beliefs. As the nurses did not seem to consider religiosity as an urgent need, they perceived that it might not matter if they excluded the introduction of religious activities to patients. In other words, some nurses felt that patients were unable to distinguish activities reflecting entertainment, cultural performance or religiously motivated events. Nevertheless, other nurses felt that it was important to facilitate patients' expressions of faith and beliefs. Nurses (Study IV) wanted to work from a holistic view of care, but felt that issues related to patients' religiosity and faith were difficult to deal with. Spiritual care as religious care awakened feelings of embarrassment and uncertainty in the nurses, who felt uncomfortable in the provision of religious care (Study IV). The nurses felt shame and contempt for care situations where patients expressed their core religious values in life (Study IV). The findings highlight that, although the nurses perceived patients' religious practice as important, they experienced multiple barriers in accommodating this in their work (Study II, IV). The nurses' own prejudices were a hindrance (in line with Study I), as well as ignorance and uncertainty (in line with Study II), and nursing home culture not being open to faith-related issues (in line with Study IV). The nurses revealed the dilemma over the relationship between their view of life and the patients' view of life. This became particularly evident in Study IV, in which nurses revealed great discord when caring for the patients' religious needs. Religious expressions were, in one sense, stigmatized in the 'homes'

and caused the nurses to avoid dealing with particularly difficult incidents related to patients' expressions of faith.

Previous research indicates that nurses' religious affiliation positively affects the provision of spiritual care compared with colleagues with no religious faith (Lundmark, 2006; Chan, 2010). This was also the case in a study by Lucchetti et al. (2014) in which they found that many nurses prayed with the patients, demonstrating a strong interface between religion and healthcare. Prayers are considered as a coping strategy in much research (Beuscher & Beck, 2008; Beuscher & Grando, 2009; Snider & McPhedran, 2014), despite guidelines often suggesting that healthcare personnel should not pray with patients (Lucchetti et al., 2014). One of the nurses in Study II said that she had prayed together with the patient in the nursing home and that the patient appreciated this.

Another main issue in the findings (Study IV) was that nurses did not take account of patients' concerns and their need to talk about death, despite patients being near the end of their lives. The nurses (Studies III and IV) sometimes avoided talking about death-related questions with the patients, because they felt that patients were unable to conduct or complete conversations about death. In this way nurses restricted patients' possibilities of articulating their core values related to life and death (Thoresen, 2003). In a study by De Roo et al. (2014), the impression of spouses/partners was that only 56% ( $n = 233$ ) of patients with dementia die peacefully. The study showed that patients with dementia were more likely to die peacefully if they had a perceived moderate (versus no) influence of religious affiliation on end-of-life decision-making policies. These findings should be investigated further in dementia care settings.

Nurses in the empirical studies (Studies II and IV) felt limited freedom associated with caring for patients' religious and faith-related needs in the nursing homes. They described several cultural challenges in line with findings from other studies (DeMarinis, Scheffel-Birath & Hansagi, 2009; Ulland & Demarinis, 2014). The first challenge related to a nursing profession in which the nurses were uncertain of their role in relation to patients' needs for religious expression. The second challenge related to the culture in Norwegian society, in which nurses perceived that society was not open to religiosity in general. The third challenge to which nurses referred was the culture in the nursing homes not being open to patients' religious expression. Kleinman, Das & Lock (1996) argue that people's different suffering is in many

cases silent, restricted by the collective, cultural and political norms of society. The inability to communicate pain isolates the sufferer. Many people with dementia lack language skills due to the progress of the disease, and cannot manage to find the right words for the experience of spiritual suffering. Nurses did not discuss the aspects of spiritual suffering in patients' lives. It seemed that religious and spiritual expressions were oppressed from both the 'outside' and the 'inside' of the 'home' because of the cultural restrictions. We did not expect the cultural restrictions in society to be that strong, especially as Study IV revealed.

### **7.2.2 General spiritual care**

*Spiritual care in terms of togetherness.* Nurses in the empirical studies (Study III) perceived that patients experienced connectedness to other people in relationships, and relationships promoted patients' experiences of togetherness. The nurses emphasized that good relationships with patients helped them to convey reciprocity and love towards them. What characterized the togetherness between the patients with dementia and the nurses?

The findings in the empirical studies (Study III) show that the nurses emphasized helping the patients establish contact with other people such as fellow residents, spouses/partners or other care personnel, to reduce patients' experiences of isolation and promote their experience of togetherness and belonging. Nurses (Study III) did not explore extensively the quality or the characteristics in the interaction between themselves and patients. Kitwood (1997) highlights that the need for assistance of people with dementia must be included in relationships with other people. Social interactions in the form of help establishing and maintaining relationships are also important because patients with dementia tend not to take any initiative in social interactions (Edvardsson et al., 2008). A challenge in dementia nursing is that patients often isolate themselves from social interactions as a result of their cognitive impairment (Engedal et al., 2009). At the same time, the patients need to experience feelings of cohesion and togetherness, and avoid the feelings of loneliness (Erichsen & Bussing, 2013; Rokstad et al., 2013). Getting to know a person with dementia provided an opportunity for nurses to understand the person's meaning and purpose (Study I). Schnell (2011) states that meaningfulness is associated with the person's appraisal of life as 'belonging'. The experience of belonging seems fundamental to human lives (Cooney, 2014). This is similar to what Luke et al. (2013) found when they examined how nurses in relationships could stimulate patients' memories of the past and present, and thus increase patients' sense of

confidence. The nurses (Study III) felt that spiritual care in the form of promoting patients' experiences of connectedness to other people in relationships increased patients' experiences of belonging, because this was important in spiritual care. Cooney et al. (2013) state that connection in relationships functions best when it occurs as a form of reciprocity. This is supported by research. O'Rourke et al. (2015) found, in their meta-synthesis, that connectedness in relationships promoted patients' sense of wellness and quality of life.

*Spiritual care providing meaningful activities in everyday life.* Nurses in the empirical studies claimed that patients enjoyed activities such as walking in the garden, listening to birds singing, reading a newspaper or enjoying a piece of chocolate (Study II). It seems as though attending to basic needs provided the nurses with an opportunity to appreciate patients' vulnerability and humanness (Study I). Nurses observed patients' behaviour as signs of patient participation, concentration, smiles and joy or, conversely, frustration and anger in relation to the activities in which they participated. Nevertheless, there were limited discussions about what had previously created meaning and purpose in patients' lives, and not many of the nurses referred to patients' previous life histories before they came to the nursing home. One question is what kind of activities have meaning for people with dementia. Previous research in dementia care provides some answers to this question. Bepthage (2009) argues that spiritual care means reaffirming patients' personhood by strengthening their individuality and life history. Other studies associate spiritual care in dementia with nurses showing compassion for the person with dementia, and in this way reinforcing the patient's experience of self-value (Goodall, 2009; Timmins et al., 2014). The findings show that nurses were uncertain how they could relate to the personality of people with dementia, in the light of the patients' cognitive impairment. The nurses were also unsure how major were the changes in patients' perceptions of themselves.

The nurses in the empirical studies (Studies III and IV) felt that the activities in themselves were a target for people with dementia, and furthermore expressed that they did not believe that patients were able to reflect on the meaning in life due to the cognitive impairment (Study IV). Thus, the nurses put less emphasis on the content of the activity for each patient and limited the emphasis on patients' experience of meaningfulness or meaninglessness. There is a question to what extent nurses in fact facilitated patients' connectedness to the environment through familiar activities, because they offered a limited focus on patients' previous interests, values and life history. Phinney et al. (2007) stated in their study that meaningful

activities for people with dementia were poorly understood, but they found that patients were engaged when they were occupied with activities that had previously been favourite hobbies, emphasizing the importance of work-related activities. This is also confirmed by a study of Vernooij-Dassen (2007), in which the author found that activities for people with dementia became purposive or meaningful through the patients feeling pleasure about them. This is similar to what nurses in this dissertation (Study III) experienced when patients provided feedback about the activities, mostly non-verbally. An additional challenge was that patients could be passive, tired and with no initiative. Nevertheless, nurses (Study III) felt that patients' inaction could be perceived as positive because they put limits on themselves. The nurses found that they needed to find a balance between introducing activities and meeting patients' needs for rest (Study III and I).

Schnell (2011) states that meaningfulness is associated with a person's appraisal of life as 'coherent and significant'. Nurses in this project didn't think much about patients' need for coherence. The nurses' intention was to help patients achieve well-being, similar to the descriptions of self-transcendent experiences that are in line with Reed (1992), although the nurses lacked descriptive theoretical concepts. Discussion of the findings in the empirical studies points to nurses understanding and practising spiritual care by promoting the connectedness to self of patients with dementia through facilitation of moments of serenity, in which the patients could experience moments of inner peace; the nurses found this challenging, however.

*Integration of spiritual care into general care.* The nurses in this dissertation (Study III) considered spiritual care to be fundamental to and interwoven into general care; they described part of spiritual care as patients' need for closeness in the form of a hug or holding hands. However, the nurses (Studies II and III) felt that in practice their greatest focus was on patients' physical and emotional needs, describing spiritual care as sitting by the bedside, showing love, stroking a patient's cheek, smiling and sitting quietly with the patient. Thus, the nurses felt that spiritual care was present in daily care by emphasizing *how* the care situation was dealt with. Nurses believed that physical care also affected the spiritual dimension of patients' lives. To create 'good moments' for the patients, the nurses used music and sensory stimulation. Thus, the nurses associated music and the outcome of sensory stimulation with patients' spirituality; it is likely that the nurses tried to facilitate patients' experience of peace through a sense of spiritual well-being (Erichsen & Bussing, 2013). This could also be seen in

a Swedish study by Lundmark (2005), in which the nurses undertook the creation of an atmosphere of safety and compassion. Research describes spiritual care as being aware of the other people's reality (Sawatzky & Pesut, 2005), which is in line with some perspectives of the empirical studies (Studies II and III) – spiritual care was considered to be intuitive, tacit and part of nurses' general care. This last point refers to a broader perspective of spirituality as discussed in the following.

Nurses in this dissertation (Study III) argued that spiritual care was characterized by nurses' intuition, very similar to previous nursing research on spiritual care (Sawatzky & Pesut, 2005; Timmins et al., 2014). Intuition and tacit knowledge are a way of approaching the spirituality of the patient with dementia, because many patients cannot communicate their spirituality with words. Research reveals that connections between nurses and patients, in general, are strengthened by nurses' use of intuition, allowing wordless communication (Thoresen et al., 2011; Delmar, 2012). Neuweg (2004) claims that tacit knowledge means to 'do something intelligently in an intuitive manner' (p. 7). Tacit knowledge is based on nurses' experience and competence, so it is a complex structure of experience-guided working (Herbig et al., 2001). The findings in the empirical Studies II and III seem nevertheless to be a paradox. The nurses (Studies II and III) emphasized the need for spiritual care in the lives of patients with dementia, yet they seldom talked about spiritual care in the 'home'. Although the nurses lacked experience, competence and knowledge about spiritual care, they claimed to work altruistically, intuitively and tacitly when providing such care. What was the foundation for the nurses' professional caring practice? It seems as though nursing research emphasizes intuition and tacit knowledge in spiritual care more than other traditions such as psychology of religion. Thus, nurses linked spiritual care to experience-based practice in general, rather than to theoretical evidence of spiritual care in particular.

In summary, this part of the discussion revealed that nurses had a broad understanding of spirituality. They seemed confident with general spiritual care as caretaking of the patients' need for well-being and relational aspects, in line with horizontally oriented self-transcendence (Schnell, 2011). This kind of care is very similar to dementia care in general. The nurses felt less safe when caring for a particular religious spiritual care. However, they described spiritual care as facilitating patients' expressions of faith and beliefs. Religiosity, as a search for the sacred, was not elaborated on, although 'the sacred' is a vital part of the understanding of spirituality in research (Pargament et al., 2014). One reason may be the lack

of theoretical knowledge and the nurses' practice not being grounded in research, but rather in personal and experience-based knowledge. In addition, the nurses felt that they needed help from priests or religious leaders to care for patients' religious needs. This revealed another major uncertainty in the nurses' working life world. The findings of this doctoral project indicate that nurses experience their theoretical and empirical knowledge of patients' spiritual needs and spiritual care as being sparse. The need to rely on the competence of priests is a strong signal that nurses feel they have too little knowledge about providing spiritual care in the face of such a demanding group of people as those in nursing homes who have dementia.

## **7.3 Methodological issues**

In the following is presented an overall assessment of methodological considerations in Studies I, II, III and IV, based on the COREQ (Tong et al., 2007).

### **7.3.1 Research team and reflexivity**

The research team in the current project consisted of three female researchers and one man. All four had different clinical experience, although one was educated in theology (LJD, Professor of Theology); the other three were registered nurses (KK, DPhil, professor; SH, DPhil, professor; and LSØ, lecturer). All researchers had experience of previous research (Tong et al., 2007). The researchers who attended the interviews (LSØ and KK) did not know the participants and the interview situation was based on a safe atmosphere of mutual dialogue and listening. As researchers, we are aware that we are part of the research process and our pre-understanding would affect how we interpreted the data (Touhy et al., 2013). We sought to be open and reflective in our pre-understanding. As researchers, we challenged each other through discussion of each individual's understanding of the findings. In this way we could reach a more thorough understanding of the informants' statements. This led to continuity in the research process, but also to an in-depth reflection on our own research role, as described in Chapter 4.

### **7.3.2 Study design**

Focus-group interviews are a useful method for investigating people's values and beliefs (Bowling, 2002). We wanted to take advantage of the possibility of examining what participants thought, but also how they were thinking, why they were thinking in that way, their understanding and their priorities (Kizinger, 1995; Bowling, 2002). Focus-group interviews are well suited to the exploration of experiences and opinions in people's lives (Malterud, 2012). Different perspectives of a certain reality can be explored in a single interview. Focus groups have the dynamics to pursue a topic in greater depth, and can generate ideas and insights more deeply than individual interviews. Interpretative phenomenology was an appropriate choice of method because understanding, explanation and the quest for meaning were central to the interview. The discussion in the focus groups helped to uncover each person's perspectives of each individual's assumptions, which were challenged by the other group members (Bradbury-Jones et al., 2009).

### **7.3.3 Participants**

Selection of participants for the focus-group study was influenced by some practical considerations because of the care situation in each home. We included care workers, not just RNs, because more care workers than RNs are employed in nursing homes. RNs usually have more administrative tasks and fewer direct care functions with patients. Rather than contacting additional nursing homes, it suited us to include care workers who worked closely with the patients to complement the focus groups. The advantage of the purposive sample in Studies II, III and IV was that some nurses and care workers could have reservations about the subject because it touched on deeper values in some people's lives. This meant that focus-group participants with some interest in the topic could contribute actively to the conversations without experiencing major inner conflicts related to the theme's content. Each focus group created the data jointly. It may look like a weakness that just one male nurse participated, but we assumed that this reflected the very few male nurses generally working in Norwegian nursing homes, besides which very few men in general work in dementia care.

### **7.3.4 Data collection**

We found that the participants felt that it was beneficial to discuss spiritual care in focus groups during the interviews. Joint conversations helped to increase knowledge and

awareness of the theme's relevance in practice. As researchers we did not attempt to separate ourselves from the focus-group participants, but partook in the focus-group discussion (compare interpretive phenomenology) (Willig, 2013). Data emerged through a mutual interpretation of what the participants said in the group. Focus groups are a place where nurses and care workers could think, learn and reflect together. Experiential knowledge proved to be important, and the discussions in the focus groups contributed to a greater awareness of the topic. Risk biases in multistage focus groups are a pressure towards consensus, which means that the participants express common understanding and attitudes when in fact they have divergent opinions. We were aware of this and continually asked complementary questions. On the other hand, several group conversations opened up the possibilities of developing communication between participants in a deeper way, and helped to open up different opinions and perspectives.

In the application of the topic guide, we questioned whether we could have used a more structured interview guide. It could have helped to have been able follow up individual topics to a greater extent than we did. As a result of this, the role of the facilitator could have been withdrawn even more. Nevertheless, openness contributed to how we obtained a lot of the information, and many associations with the theme.

### **7.3.5 Analysis and findings**

To understand is to explore one's own horizon of understanding (Gadamer & Jordheim, 2003). Our pre-understanding as researchers has been clarified over the project (see Chapter 2). We worked with the aim of being as transparent as possible in the work process. All four research studies worked with analysis of the interview text, which was discussed in depth, based on each individual's understanding of it. This was a way of working towards a detailed description of meaning in the text. Data were analysed and discussed with other researchers and compared with recent research in the field (Munhall, 2012). Throughout the project we attempted to be open to reflections and difficult questions about the data analysis. Throughout the data analysis, we found that follow-up interviews helped to deepen the topic further. Nurses and care workers managed give words to difficult aspects of spiritual care, as revealed by some key areas developed to a limited extent in previous research.

### **7.3.6 Strengths and limitations**

This doctoral project has changed over its course. Initially, we planned to conduct four focus-group interviews, one at each of the four nursing homes. After completion of two focus-group interviews, we discussed the possibility of expanding the study because the nurses provided rich and extensive information about the topic in an unexpected way. The choice caused us to remove the planned observation study from the project. In retrospect, we perceived that the changes did not weaken the project, although it would have been interesting to compile patients' perspectives through observations in the nursing homes. Nevertheless, we got the opportunity to investigate patients' perspectives through the meta-synthesis.

## 8 Conclusions

The main purpose of this doctoral thesis was to explore how RNs and care workers carry out spiritual care in nursing homes, by focusing on their experiences and perspectives of the spiritual needs of people with dementias.

The way in which nurses provided spiritual care was considered to be tacit, intuitive and altruistic, and a part of general care. The nurses' understanding of the meaning of spiritual care was to meet patients' spiritual need for calmness and serenity, self-transcendence, inner peace, well-being and connectedness in relation to self, other people and God/a deity. Such relationships promoted a patient's sense of belonging and togetherness.

Nurses facilitated activities that promoted patients' experiences of significance and meaning in everyday life, but their understanding of the meaning of this care for people with dementia seemed to be blurred. Nurses emphasized taking care of patients' expressions of faith and beliefs, although they did not have a clear understanding of the significance of religiosity in patients' lives. Nurses shared their patients' religious beliefs and faith to a limited extent, which affected their practice of caring. Some nurses experienced challenges and personal barriers by feeling embarrassed, ashamed and alienated in relation to the religious practice in nursing homes. It seemed as if the nurses favoured general spiritual care through subjective knowledge, but had less focus on particular religious spiritual care. Furthermore, nurses felt that they lacked knowledge and expertise to provide spiritual care. It was not common to talk about or incorporate spiritual care into dementia care in nursing homes, because the culture was not open to discussion of spiritual and religious concerns.

# 9 Implications for nursing practice

## **Development of educational programmes**

This dissertation reveals a need to strengthen nurses' knowledge and competence in spiritual care to meet patients' spiritual needs. Joint reflection and discussions between nurses are essential to develop skills and knowledge about spiritual care for people with dementia. It seems to be necessary to develop educational programmes adapted to nursing practice, which are aimed at increasing nurses' competence in spiritual care in practice. There are several models of spiritual care in research, but most of them are aimed at cognitively healthy people. Educational nursing institutions should take the responsibility for improving the education on spiritual care.

## **To work across disciplines and professions**

This thesis has highlighted spiritual care getting insufficient attention for nurses' caring practice in nursing homes. Thus, spiritual care needs to be 'moved' from the private commitment of each individual nurse to a public care understanding. There seems to be a need to strengthen interdisciplinary and cross-professional collaboration of nurses and priests/religious leaders to develop spiritual care in nursing homes to a higher level than at present. Nurses and priests can achieve much through common experience and exchange of knowledge.

# 10 Recommendations for further research

This dissertation has pointed to several aspects needing investigation with regard to spiritual care for people in nursing homes who have dementia. Two of those aspects were mentioned in particular.

## **'Meaning' in dementia**

There is a need to investigate the kinds of sources on which patients with dementia draw to create meaning, and how nurses may assess and evaluate patients' experience of meaning in nursing homes. Furthermore, there seems to be a need for research aimed at developing some common frameworks for understanding spiritual care within dementia care.

## **Investigate the influence of the caring culture**

There seems to be a need to explore different kinds of restrictions and/or challenges that nurses experience in their practice of spiritual care. In addition, this dissertation has revealed that there is a need to investigate the culture of which nurses are a part and under which they work in nursing homes, and to investigate how nurses may provide spiritual care for people in nursing homes who have dementia, because of an increasingly more pluralistic and multi-ethnic society.

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## Spiritual care in dementia nursing. A qualitative, exploratory study.

### Errata

- p VII Punctuation marks (til seg selv, andre og Gud// guddom) to (til seg selv, andre og Gud/ guddom)
- p VII Punctuation marks (helsefagarbeidere//omsorgsarbeidere//hjelpepleiere) to (helsefagarbeidere/ omsorgsarbeidere/ hjelpepleiere)
- p IX Change: *Journal of Holistic Nursing*. Article ID: JHN-14-Dec-0127, to *Dementia: the international journal of social research and practice*. Article ID: DEM-15-0136.
- Appendix 1 Change: *Journal of Holistic Nursing*. Article ID: JHN-14-Dec-0127, to *Dementia: the international journal of social research and practice*. Article ID: DEM-15-0136.
- p XIII Table 1. Overview **over** Studies I, II, III and IV to Table 1. Overview of Studies I, II, III and IV.
- p XIII Table 2. Noblit and Hare's phases of conducting a meta-synthesis to Table 2. Noblit and Hare's seven phases of conducting a meta-synthesis
- p 49 **6.4.1** Comprehensive understanding. Changes to 6.5 Comprehensive understanding