

SUPPORTING THE SPIRITUALITY OF OLDER PEOPLE WITH DEMENTIA IN THEIR CARING AND LIVING ENVIRONMENTS

Kristiina Juudin



SUPPORTING THE SPIRITUALITY OF OLDER PEOPLE WITH DEMENTIA IN THEIR CARING AND LIVING ENVIRONMENTS

Kristiina Juudin

University of Turku

Faculty of Medicine
Department of Nursing Science
Nursing Science
Doctoral Programme in Nursing Science

Supervised by

Professor Riitta Suhonen, RN, PhD Department of Nursing Science University of Turku Finland Professor Andreas Charalambous, RN, PhD Department of Nursing Science Cyprus University of Technology Cyprus

Reviewed by

Professor Camilla Koskinen, RN, PhD Department of Caring and Ethics Faculty of Health Science University of Stavanger Norway

Professor Peter Nynäs
Faculty of Arts, Psychology and Theology
Åbo Akademi University
Finland

Opponent

Professor Fiona Timmins, PhD School of Nursing, Midwifery and Health Systems University College Dublin Ireland

The originality of this publication has been checked in accordance with the University of Turku quality assurance system using the Turnitin OriginalityCheck service.

ISBN 978-951-29-9901-9 (PRINT) ISBN 978-951-29-9902-6 (PDF) ISSN 0355-9483 (Print) ISSN 2343-3213 (Online) Painosalama, Turku, Finland 2024 UNIVERSITY OF TURKU

Faculty of Medicine

Department of Nursing Science

KRISTIINA JUUDIN: Supporting the Spirituality of Older People with

Dementia in Their Caring and Living Environments

Doctoral Dissertation, 147 pp.

Doctoral Programme in Nursing Science

October 2024

ABSTRACT

Supporting spirituality is essential to high-quality nursing care of older people with dementia. The aim of this study was to achieve a comprehensive understanding of supporting the spirituality of older people living with dementia in their caring and living environments. First, a narrative literature review on spiritual support of older people living with dementia was conducted. Secondly, in two hermeneutic-phenomenological interview studies the lived experiences of nurses (n=17) and older people (n=10) together with their family members (n=9) were inquired. In the latter sub-study, spiritual-supportive caring and living environment was analysed utilising photo-elicitation. A total of 75 photographs were included in the analysis.

Results revealed that supporting the spirituality of older people living with dementia was concerned with supporting religious activity, enabling connections, nurses' reflections on their own spirituality, and nonverbal communication. From the perspective of nurses, supporting the spirituality of older people living with dementia was seen as understanding their spirituality within a framework of personcenteredness and individuality. Spiritual needs were met by approaching people with dementia as valuable humans as well as supporting their personal philosophy of life. According to the experiences of the older people living with dementia and their family members, their personalised spirituality can be supported through four elements of spirituality: religion, meaningful relationships, nature, and arts. Personal sense of meaning was central to experiences of spiritual support. Spirituality was seen as a continuum of human life, manifested through caring and living environment even when older person living with dementia was unable to express it. The experiences of the nursing environment that supports spirituality were summarized into three questions: "Where do I belong?", "What remains of me in the world?" and "Where am I going?" Caring and living environment that supports spirituality seeks answers to these questions together with older people with dementia, their family members, significant others, and nursing professionals.

A descriptive theory of supporting the spirituality of older people with dementia in their caring and living environments was derived from this study. This may improve the nursing care of older people with dementia by considering their spiritual needs.

KEYWORDS: dementia, environment, hermeneutic phenomenology, older people, spirituality

TURUN YLIOPISTO

Lääketieteellinen tiedekunta, Hoitotieteen laitos

Hoitotiede

KRISTIINA JUUDIN: Ikääntyneiden muistisairaiden henkisyyden tukeminen

heidän hoito- ja elinympäristöissään

Väitöskirja, 147 s.

Hoitotieteen tohtoriohjelma

Lokakuu 2024

TIIVISTELMÄ

Henkisyyden tukeminen on keskeistä laadukkaassa ikääntyneiden muistisairaiden hoitotyössä. Tämän tutkimuksen tavoitteena oli ymmärtää henkisyyden tukemista ikääntyneiden muistisairaiden hoitoympäristöissä. Aluksi toteutettiin narratiivinen kirjallisuuskatsaus ikääntyneiden muistisairaiden henkisyyden tukemisesta. Seuraavaksi toteutettiin kaksi hermeneuttis-fenomenologista haastattelututkimusta, joissa selvitettiin hoitohenkilökunnan (n=17), ikääntyneiden muistisairaiden (n=10) ja heidän läheistensä (n=9) kokemuksia. Lopuksi analysoitiin henkisyyttä tukevaa hoitotyön ympäristöä hyödyntäen valokuvausmenetelmää. Analyysiin sisällytettiin yhteensä 75 valokuvaa.

Henkisyyden tukeminen ikääntyneiden muistisairaiden hoitotyössä on uskonnollisen toimijuuden tukemista, yhteyden mahdollistamista, hoitajien oman henkisyyden reflektointia ja sanatonta viestintää. Hoitajat tunnistavat ikääntyneiden muistisairaiden henkisiä tarpeita sekä sanallisen että sanattoman viestinnän kautta ja perehtymällä ikääntyneiden muistisairaiden henkiseen ja hengelliseen taustaan. Henkisiin tarpeisiin vastaaminen merkitsee ikääntyneen muistisairaan kohtaamista arvokkaana ihmisenä sekä hänen henkilökohtaisen elämänfilosofiansa tukemista hoitotyössä. Henkisyyttä voidaan tukea hoitotyössä yksilöllisesti eri elementtien kautta. Näitä elementtejä ovat uskonto, merkitykselliset ihmissuhteet, luonto ja taide. Henkilökohtainen tarkoituksen ja merkityksen tunne on keskeistä henkisen tuen kokemuksissa. Henkisyys nähtiin ihmiselämän jatkumona, joka ilmenee ympäristön kautta silloinkin, kun ikääntynyt muistisairas ei kykene itse ilmaisemaan sitä. Ikääntyneiden muistisairaiden ja heidän läheistensä kokemukset henkisyyttä tukevasta hoitotyön ympäristöstä tiivistettiin kolmeen eksistentiaaliseen kysymykseen: "Mihin minä kuulun?", "Mitä minusta jää jäljelle?" ja "Minne minä olen menossa?" Henkisyyttä tukeva hoitotyön ympäristö etsii vastauksia näihin kysymyksiin yhdessä ikääntyneen muistisairaan ihmisen, hänen läheistensä ja muiden hänen hoitoonsa osallistuvien kanssa.

Tutkimuksen pohjalta luotiin kuvaileva teoria ikääntyneiden muistisairaiden henkisyyden tukemisesta heidän elin- ja hoitoympäristössään. Tämä voi edistää ikääntyneiden muistisairaiden henkisten tarpeiden huomioimista hoitotyössä.

AVAINSANAT: hengellinen tuki, hengellisyys, henkisyys, hermeneuttinen fenomenologia, hoitotyön ympäristö, ikääntyneet, muistisairaus

Table of Contents

List	of Ta	bles, Figures and Appendices	8
Abb	revia	tions	9
List	of O	riginal Publications	. 10
1	Intro	oduction	. 11
2	Rev 2.1	The concept of spirituality	17 17 19 19 23
		Spirituality of people with dementia within the context of nursing care	24
	2.3	spirituality	. 28
3	Aim	s of the Study	. 30
4	Mat 4.1	Study design	35 35
	4.2	4.1.2 Hermeneutic phenomenology. Setting, sampling and sample. 4.2.1 Setting	39 39 39 40 42
	4.3	4.2.3.2 Photography	44 44

		4.3	3.1.2 Ricoeur's theory of interpretation	46
		4.3.2 An	alytic phase: Inductive thematic content analysis	
	4.4	Ethical co	luding photo-analysisnsiderations	48 49
_	Daar	.140		5 0
5				
	5.1	5.1.1 Su	g the spirituality of older people with dementia pporting the spirituality of older people with	
		der	mentia in literature	52
		der	pporting the spirituality of older people with mentia from the perspective of nursing	50
		pro	ofessionalsthe parametric of	53
			pporting the spirituality from the perspective of er people with dementia and their family	
			mbers	54
	5.2	Caring an	d living environment supporting the spirituality of	
		older peop	ole with dementia – ways of being-in-the-world	57
	5.3	Summary	of the main results	59
6	Disc	ussion		65
•	6.1	Reflection	of the methods	65
	6.2	Reflection	of the results	68
	6.3	Limitations	s and rigor of the study	73
	6.4	Suggestio	ns for future research	<u>76</u>
	6.5	Practical i	mplications	/ /
7	Con	clusions.		81
Ackı	nowle	dgement	:s	83
		J		
Refe	renc	es		86
Oria	inal F	ublicatio	ns	99

List of Tables, Figures and Appendices

Figure 1.	PubMed from 1985 through 2022	14
Figure 2.	Hermeneutic phenomenological circle into the	17
1 1ga10 2.	comprehensive understanding	16
Figure 3.	Research questions and study designs.	31
Figure 4.	Study Phases and Sub-Studies.	32
Figure 5.	The circle of the narrative literature review	36
Figure 6.	Qualitative inductive data analysis conducted in step 2	
Figure 7.	Prerequisites for, elements of and barriers to	
•	supporting the spirituality of older people with dementia	
	in nursing care	53
Figure 8.	Illustration of nursing professionals' experiences of	
	supporting the spirituality of older people living with	
	dementia.	54
Figure 9.	Supporting the spirituality from the perspective of older	
F: 10	people with dementia and their family members	56
Figure 10.	Spirituality supportive caring and living environment of	E0
Figure 11.	older people with dementia Examples of spirituality-supportive caring and living	58
rigule i i.	environment in photographs.	59
Figure 12.	The components of the descriptive theory on	00
rigaro 12.	supporting the spirituality of older people with dementia	
	in their caring and living environments	62
	gg	
Table 1.	Definitions of spirituality	21
Table 2.	Phases, research questions, designs, samples, data	
	collection and analysis of sub-studies	33
Table 3.	The inclusion criteria	40
Table 4.	Steps of the evaluation of saturation	43
Table 5.	An example of meaning units, condensed meaning	
-	units and codes	46
Table 6.	Process of interpretation	48
Table 7.	Example of codes as building blocks of themes	49
Table 8.	Results and outcomes of research steps.	
Table 9.	Actions taken to ensure rigor	/5

Abbreviations

CINAHL Cumulative Index to Nursing and Allied Health Literature MEDLINE Medical Literature Analysis and Retrieval System Online

MSAH Finnish Ministry of Social Affairs and Health

PUBMED National Centre for Biotechnology Information's Entrez retrieval

system

RQ Research Question

STM Sosiaali- ja terveysministeriö (Ministry of Social Affairs and Health)

WHO World Health Organization
WMA World Medical Association

List of Original Publications

This dissertation is based on the following original publications, which are referred to in the text by their Roman numerals:

- Toivonen K, Stolt M and Suhonen R. 2015. Nursing support of the spiritual needs of older adults living with dementia. A narrative literature review. *Holistic Nursing Practice*, 29(5): 303-312. doi:10.1097/HNP.000000000000101.
- II Toivonen K, Charalambous A and Suhonen R. 2018. Supporting spirituality in the care of older people living with dementia A hermeneutic phenomenological inquiry into nurses' experiences. *Scandinavian Journal of Caring Sciences*, 32(2): 880-888. doi:10.1111/scs.12519.
- III Toivonen K, Charalambous A and Suhonen R. 2023. Supporting the spirituality of older people living with dementia in nursing care: A hermeneutic phenomenological inquiry into older people's and their family members' experiences. *International Journal of Older People Nursing*, 18(1):1-11. doi:10.1111/opn.12514.
- IV Toivonen K, Charalambous A and Suhonen R. 2022. A caring and living environment that supports the spirituality of older people with dementia: A hermeneutic phenomenological study. *International Journal of Nursing Studies*, 138, 104414. doi:10.1016/j.ijnurstu.2022.104414.

The original publications have been reproduced with the permission of the copyright holders.

1 Introduction

This is a study on supporting the spirituality of older people with dementia in their caring and living environments. The aim was to describe how the spirituality of older people living with dementia can be supported in their caring and living environment and to analyse which elements in those environments support their spirituality. Through this interpretive description and analysis, the aim was to achieve a comprehensive understanding of the phenomenon. The lived experiences of older people with dementia, their family members and nursing professionals were explored.

Spirituality is a concept deeply rooted in human nature whether the person is religious or not (Murgia et al. 2020). Therefore, supporting spirituality is considered as an essential part of good holistic nursing care of older people living with dementia (Ennis et al. 2013). In holistic person-centred nursing, physical, psychological, social, environmental, and spiritual aspects of personality are considered. This person-centeredness is emphasized in the nursing care of older people with dementia (Edvardsson et al. 2014) and includes seeing personal beliefs and lived life experiences as part of the person with dementia. Accordingly, a person is not defined only by dementia. (Gallagher & Warren 2019.) Instead, taking spirituality into account as a part of the personality (Piedmont 1999) values the inner being of the person with dementia (Daly et al. 2019) and respects person's dignity (Johnston et al. 2016).

The pace of population aging has accelerated globally and at the same time the number of older people living with dementia has been increasing, as old age is the most significant risk factor for dementia (WHO 2021). The prevalence of dementia will increase, with a projected rise from 50 million to 151 million people living with dementia worldwide by 2050 (Prince et al. 2014). Dementia is not a single disease but refers to a condition resulting from several different diseases (Alzheimers Association 2023). In dementia, memory and cognitive abilities have weakened to the extent that interferes with everyday life. Dementia can be seen as a public global health threat that increases health disparities and slows economic growth (Counts et al. 2021). Dementia may also have a detrimental effect on the economy at the individual level (Jutkowitz et al. 2017).

The labour shortage in nursing care for individuals with dementia challenges the implementation of high-quality care for older people with dementia (Vernooij-Dasssen et al. 2009). However, they should be supported in living a full life (Fleming et al. 2023). The World Health Organization (WHO) has prepared the Global action plan on the public health response to dementia for the years 2017-2025. The target of the plan is that the people living with dementia get 'support they need to live a life with meaning and dignity'. (World Health Organization 2017.) Finland's national program on ageing also emphasizes the need for older people to experience their lives as meaningful (Ministry of Social Affairs and Health MSAH 2020). These values create the basis for ethical sustainability in the care of older people with dementia (Nyholm et al. 2018). Spiritual support may help in achieving these goals (Chen et al. 2019). This human sustainability thinking, and human care is essential for older people with dementia in the age of technology. Supporting spirituality in nursing does not require large financial resources but can be conducted through small things in everyday nursing (Carr et al. 2011).

Despite several concept analyses (eg. Emblen 1992; Tanyi 2002; Mahlungulu & Uys 2004; Buck 2006; McBrien 2006; Sessanna et al. 2007; Lazenby 2010; Gall et al. 2011; Ramezani et al. 2014; Weathers et al. 2016; Il et al. 2017; Yeşilçınar et al. 2018; Murgia et al. 2020; Tavares et al. 2022), the meaning of spirituality in nursing science remains unclear without a universally accepted definition being available (Ennis et al. 2013). The concept has been described as complex (Weathers et al. 2016) and multidimensional (Il et al. 2017) or as Jewell (2003, p. 14) puts it, a "notoriously slippery" concept. Spirituality has, in some cases, been understood as connected to religiosity (Ennis et al. 2013; Murgia et al. 2020). In other cases, the two concepts have been clearly distinguished (Ennis et al. 2013). However, it is generally agreed that also non-religious people might have their spiritual dimension (Tanyi 2002; Yeşilçınar et al. 2018).

In nursing research, the concept has usually had a broad meaning (Murgia et al. 2020). In this broad sense, spirituality is seen as a part of being human (Tanyi 2002; Ennis et al. 2013). It relates to the search for the meaning and purpose in life (Dalby et al. 2012; Yeşilçınar et al. 2018). The experience of spirituality is individual (Tanyi 2002; Daly et al. 2019). Spirituality transcends the boundaries of visible world (Weathers et al. 2016).

Spiritual support can help older people living with dementia to cope with their life-threatening disease (Carr et al. 2011; Dalby et al. 2012; Hirakawa et al. 2020). It can generate or increase hope and satisfaction in life (Wu & Koo 2016) and promote their overall well-being (Ennis et al. 2013). It can relieve anxiety and reduce restlessness (Ennis et al. 2013) as well as depression (Trivedi et al. 2016). Supporting spirituality can improve the quality of life of older people living with dementia (Ennis et al. 2013). It has been connected to lower mortality and morbidity rates

(Ennis et al. 2013). All these positive effects prompt for asking how the spirituality of older people living with dementia can be supported. However, it has been noted that the spiritual needs of older people with dementia are often ignored (Daly et al. 2019).

Kim (2010, pp. 221) has stated that 'human existence cannot be considered distinct from the context of environment'. In the quality recommendation for older people care of the Finnish Ministry of Social Affairs and Health (MSAH), an age-friendly environment is strongly featured. The environment plays a key role in securing good aging and improving services. (MSAH 2020; 2024.)

The effects of the environment on older people living with dementia have been studied from multiple perspectives (Mmako et al. 2020) including people with dementia and their family caregivers (Wu et al. 2019) as well as nursing professionals (Brennan & Doan 2023). It has been suggested that the environment affects the people with dementia more strongly than others (Feddersen & Lüdtke 2014, pp. 15). For example, green spaces have been shown to support personhood and social activity of older people with dementia (Mmako et al. 2020).

The experiences of spirituality manifest in the environment symbolically (Kim 2010). In this study, the physical, social and symbolic environments of older people with dementia were explored from their own perspective and that of their family members. The nursing environment is referred to by the term 'caring and living environment', which refers to the physical, social and symbolic environment - a multidimensional space - in which the care of older people with dementia takes place. 'Caring' refers to the comprehensiveness of nursing care and 'living' refers to that the environment of care is not a hospital or other temporary facility, but the environment where the older people live their everyday lives. The caring and living environments were home care, service housing and long-term care units.

The number of scientific articles related to spirituality has increased in recent years (Ennis et al. 2013; Wang et al. 2024; Figure 1.). However, spirituality has been studied mostly in the context of end-of-life care (Ennis et al. 2013). As a result, there is scarce research about supporting the spirituality of the older people living with dementia from the perspective of nursing professionals (Hirakawa e al. 2020) and even less research on the phenomenon from the perspective of older people living with dementia (Dalby et al. 2012; Ennis et al. 2013). Their family members' spirituality has been researched (Ennis et al. 2013) but family members' perspective on the spirituality of older people living with dementia has been researched less. Older people living with dementia have rarely themselves been informants in qualitative research (Mmako et al. 2020). Dementia can impair the ability to discuss abstract issues (Hirakawa et al. 2020), which is one of the reasons why there are few interview studies aiming to identify how older people living with

dementia experience spiritual support in nursing care. However, Trevitt and MacKinlay (2004) noted that it was possible for older people with dementia to discuss spirituality.

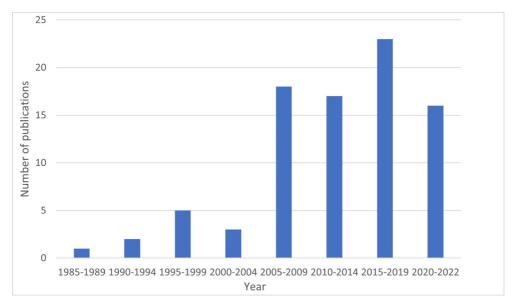


Figure 1. Number of publications on spirituality and dementia in PubMed from 1985 through 2022.

The environment that supports the spirituality of older people living with dementia has hardly been studied before. Therefore, there is still a need to study phenomena related to spirituality in the caring and living environments of older people living with dementia. World Health Organization (2017) sees it principal to engage older people with dementia themselves in the research that concerns them.

It is central to nursing work to support the dignity and individuality of a person with dementia (Bosco et al. 2019) and research shows that supporting spirituality is an integral part of this (Johnston et al. 2016). This two-phase study included four steps to understand spiritual support in the caring and living environments of older people with dementia. Firstly, earlier literature was reviewed to get an overview about spiritual support in the context of nursing care of older people with dementia (Paper I). Secondly, the perspective of nursing professionals on supporting the spirituality of older people with dementia, was studied (Paper II) and thirdly, the perspective of older people with dementia and their family members (Paper III). Finally, the spirituality-supportive caring and living environments of older people with dementia were analyzed (Paper IV).

The research was based on the nursing science paradigm. Therefore, the four basic concepts of the paradigm of nursing science, person, environment, health, and nursing (Nyatanga 2005), were central to the study. At the centre of the research were older people with dementia, who were seen as physical, psychological, social, and spiritual beings and living in interaction with their physical, social, and symbolic caring and living environment (Kim 2010, pp. 220-227). Supporting spirituality was considered to support the health of older people with dementia (e.g. McGee et al. 2018). Supporting spirituality was approached from the point of view of nursing, aiming to understand the means of nursing to support spirituality. The philosophical and methodological starting point for the research was hermeneutic phenomenology.

From this philosophical point of view, the aim was to understand the lived experiences that adhere an understanding to the participants' world about the phenomenon. The sub-studies of the research overlapped each other as each individual and group of participants brought a new understanding of the phenomenon, which was also opened by the existing literature. (Figure 2.)

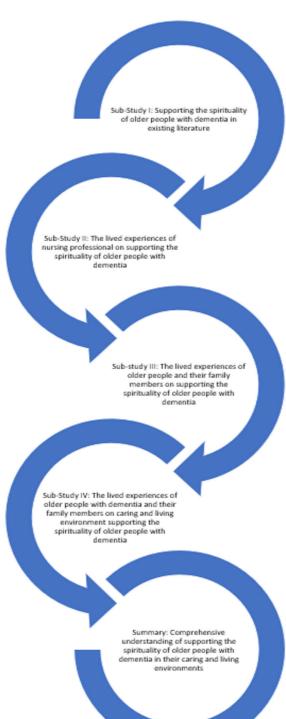


Figure 2. Hermeneutic phenomenological circle into the comprehensive understanding.

2 Review of the Literature

To elaborate the theoretical background, the phenomenon will be described in the light of the literature systematically searched in four databases: CINAHL, Cochrane Library, PubMed (Medline) and the Web of Science. In this research, the focus was on the spirituality of older people living with dementia, so in the literature reviews, the articles that focus on their caregivers' spirituality were excluded. In addition to this systematic search, manual searches were performed for example by using reference lists of relevant literature. The literature dealing with the phenomenon was extensively studied including both theoretical and empirical literature.

In this chapter, a brief overview of the history of spirituality and its research in the context of nursing will be taken. Secondly, the concept of spirituality in nursing and different ways of defining it will be explained. Thirdly, earlier research on supporting the spirituality of older people living with dementia in their caring and living environments will be reviewed. Finally, the gaps in the earlier literature on the phenomenon will be presented.

2.1 The concept of spirituality

In this chapter, the concept of spirituality from different perspectives and how the concept is understood in and as a part of caring and living environments will be described. The history and philosophy of spirituality will first be discussed. Next, the concept will be defined. Its relation to the concept of religiosity will be considered. It will also be explained what approaches and definitions of spirituality has been used in this study.

2.1.1 The history of spirituality and its research in nursing

The combination of spirituality and health has ancient roots as many religions have seen spirituality as related to health (Cohen et al. 2012; Connell 2012). Spirituality has played a central role in the history of nursing (Tanyi 2002; Connell 2012; Murgia et al. 2020) in that helping the poor and needy has included in most religions and nursing has partly developed on that basis (Connell 2012). The spiritual roots of nursing practice were particularly evident in 17th and 18th century Catholic France

and Spain. In the 18th century, nursing was not yet seen as a profession, but as a religious task. (Garrett 2021.)

Florence Nightingale highlighted spirituality as a part of high-quality nursing care (Nightingale et al. 2010, pp. 267, 382; Bruce et al. 2011; Cohen et al. 2012; Garrett 2021). Like Barbara Dossey explains in the foreword of 'Florence Nightingale's Notes on Nursing and Notes on Nursing for the Labouring Classes: Commemorative Edition with Historical Commentary', Nightingale calls for nursing professionals to be aware of the holistic healing of a person, which includes the physical, mental, emotional, social, and spiritual dimensions (Nightingdale et al. 2010, p.x). The education of nurses in its early stages was often organized by religious organizations. Nursing was seen as a spiritual vocation (McSherry & Cash 2004; Bruce et al. 2011). This has linked theology and nursing (Garrett 2021). In the mid-20th century, nursing education became more secular (Bruce et al. 2011). At the same time, the change was seen in defining spirituality. The previous definition based on religion or deity changed to the more secular definition. (McSherry & Cash 2004.)

Scientific research on the spirituality in nursing has begun relatively late (Cohen et al. 2012). Ribaudo and Takahashi (2008) identified the first study of spirituality in health care in 1944. The annual number of nursing studies on spirituality has been increasing since the 1980s (Cohen et al. 2012) since spirituality came back into vogue also in the philosophical field (Nicholls & Salazar 2018).

Research on spirituality in the care of older people living with dementia began even later than research on the spirituality in nursing generally. In PubMed search ("spiritual*"[Title] AND ("dementia"[MeSH Terms] OR "dementia"[All Fields] OR "dementias"[All Fields] OR "dementias"[All Fields])) on spirituality and dementia, 85 results were found the first of which dates from 1985. Publications began to increase clearly from 2005 onwards, as can be seen in the figure 1. This indicates an increase in the understanding of the significance of spirituality in the nursing care of older people with dementia (see also Mlinar et al. 2021).

Researching spirituality means returning to the roots of western nursing (Connell 2012) in a modern, diverse world where people's spirituality is changing and has moved beyond religions (Jewell 2003, pp. 7). Through spirituality, human defines his own position and place in the universe. This happens, for example, with the help of human relationships, religion, or mythology. (Teixeira de Menezes & Boechat 2022.) Spirituality is not about the contrast between body and soul (Jewell 2003, p. 17) but about the attitude of life that intends not to concentrate to material (Lambert et al. 2013).

2.1.2 The philosophy of spirituality

Many nursing theorists from the 1970s onwards have seen spirituality as a basic concept in nursing (Garrett 2021). For example, in Rogers' Science of Unitary Human Beings the focus was on spirituality (Rogers 1988; 1992; 1994). Rogers' theory influenced Margaret A. Newman's theory of expanding consciousness. Newman's own personal belief of the continuation of consciousness after death was central to her theory. (Sarter 1992.) In Watson's caring caritas theory (Watson 2019; Garrett 2021), the human spiritual dimension is strongly emphasized (Sarter 1992; Ramezani et al. 2014). Her theory is rooted in spiritual, Eastern philosophy. The meaning of 'soul' is emphasized as a source of an individual's innate striving to realize one's own spiritual being. (Sarter 1992.)

These theories gained great popularity in America, which is generally more religious than Europe (Garrett 2021). In these nursing theories, the concept 'spirituality' was rarely used despite of the connection of the contents of theories to spirituality. Indeed, the philosopher Pierre Hadot stated in the late 1980s that spirituality was not in vogue (Nicholls & Salazar 2018).

Spirituality has been understood differently at different times and in different cultures. From philosophical point of view, however, its basic meaning above all definitions is uniform: Spirituality refers to those elements that connect person to the purpose and meaning in life. (Dunn & Robinson-Lane 2020.) Such a view of spirituality based on existential philosophy is needed so that atheists and agnostics and other people outside religions can also place the concept in their own world of experience in diversified societies (McSherry & Cash 2004).

2.1.3 The definition of spirituality

Spirituality in nursing has become a prominent concept (Murgia et al. 2022). It is considered central to holistic nursing. (McSherry & Cash 2004.) The roots of the concept of spirituality are in Latin word 'spirit' which means breath or breathing (Murgia et al. 2020). This refers to spirituality as a life-sustaining force that has been included in some definitions of spirituality (Stoddard 1993).

No agreement has yet been reached on the definition of the concept of spirituality (Tanyi 2002; McSherry & Cash 2004; Sessanna et al. 2007; Bruce et al. 2011; Cohen et al. 2012; Murgia et al. 2020). Nevertheless, some concept analyses have been conducted within nursing discipline (e.g., Emblen 1992; Tanyi 2002; Mahlungulu & Uys 2004; Sessanna et al. 2007; Lazenby 2010; Ramezani et al. 2014; Weathers et al. 2016; Il et al. 2017; Yeşilçınar et al. 2018; Murgia et al. 2020). In CINAHL (Cumulative Index to Nursing and Allied Health Literature) search, sixteen relevant concept analyses on spirituality were found from 1989 to 2020.

The complexity of the concept of spirituality has given rise to reflection on whether it can be operationalized and measured (Ennis & Kazer 2013). It has been suggested that, in the case of spirituality, imperfection in the definition of the concept is essential, as spirituality is a highly subjective phenomenon (Bruce et al. 2011). On the other hand, an overly broad understanding of the concept has been feared to decentralize it completely irrelevant (Jewell 2003, p. 14; McSherry & Cash 2004). As Taylor (2023) states: "If boundaries are overly broad, then everything, and yet nothing is spiritual." However, spirituality can be understood to different extents (Bruce et al. 2011; Cohen et al. 2012). In the narrowest sense, it means a system of beliefs and values related to religion (Sessanna et al. 2007) excluding many people (Jewell 2003, p. 14). At its broadest, it is a metaphysical concept related to the search for the purpose and meaning in life (Sessanna et al. 2007).

In their taxonomy, McSherry and Cash (2004) explained spirituality as a continuum between religious and secular meaning. It has often been highlighted that spirituality may or may not be manifested through religion (e.g. Tanyi 2002). The concept of spirituality has also been explained through the vertical and horizontal dimensions. The vertical dimension is related to other human beings and the horizontal dimension to God or a higher power. (Linzer 2006.) These two dimensions of spirituality have been considered by some researchers (Canda 1988; Katsuno 2003).

Spirituality is considered as an element of being human among physical, psychological, and social elements (McSherry & Cash 2004). Understanding and explaining the relationship between these elements is challenging. They are partly overlapping. (Jewell 2003, p. 17.) Spirituality has also been seen as a concern with the nonhuman environment (Canda 1988; Katsuno 2003). The concept is culturally bound. (Bruce et al. 2011.)

Spirituality is concerned with searching for meaning in life (Canda 1988; Tanyi 2002; Katsuno 2003) and the source of hope (Tanyi 2002; Mahlungulu & Uys 2004). As such, its manifestation and understanding are very individual and dependent on the personal worldview of everyone (McSherry & Cash 2004). Furthermore, spirituality has been regarded as a source of individuality and personality (Stoddard 1993; Murgia et al. 2020) helping individuals to reach the level they want to reach in their being (Tanyi 2002). Some definitions of the concept are presented in Table 1. These definitions show how broad the concept of spirituality is and clearly demonstrates the many facets of the concept.

 Table 1.
 Definitions of spirituality.

DEFINITION	AUTHOR	YEAR
Concern with the human quest for personal meaning and mutually fulfilling relationships among people, the nonhuman environment, and for some, God.	Canda, E.	1988
Spirituality is understood as the life principle that pervades a person's entire being, specifically, their volitional, emotional, moral-ethical, intellectual and physical dimensions, generating a capacity for transcendent values. The spiritual dimension integrates and transcends biological and psycho-social nature.	Stoddard, G.	1993
That which lies at the core of each person's being, an essential dimension which brings meaning to life. It is acknowledged that spirituality is not constituted only by religious practices, but must be understood more broadly, as relationship with God, however God or ultimate meaning is perceived by the person, and in relationship with other people.		2001
Spirituality is a personal search for meaning and purpose in life, which may or may not be related to religion. It entails connection to self-chosen and/or religious beliefs, values, and practices that give meaning to life, thereby inspiring and motivating individuals to achieve their optimal being. This connection brings faith, hope, peace, and empowerment. The results are joy, forgiveness of oneself and others, awareness and acceptance of hardship and mortality, a heightened sense of physical and emotional wellbeing, and the ability to transcend beyond the infirmities of existence.		2002
A belief in a higher or supreme being, not necessarily in God, which integrates self, relationship with others and with the world, and gives meaning and purpose in one's life.	Katsuno, T.	2003
Spirituality gives us a sense of personhood and individuality. It is the guiding force behind our uniqueness and acts as an inner source of power and energy, which makes us 'tick over' as a person. Spirituality is the inner, intangible dimension that motivates us to be connected with others and our surrounding. It drives us to search for meaning and purpose and establish positive and trusting relationships with others.		2004
Spirituality is an individual's belief, developed through the lifespan, that influences a person's interpretation of morals, faith, love, trust, suffering, and God. It guides a person's view of the world and self, providing structure, purpose, and meaning to everyday activities.	Grando V.	2009
Spirituality is what gives us hope, meaning and purpose, it is fundamentally human.	Rogers M.	2016
Spirituality is a way of being in the world in which a person feels a sense of connectedness to self, others, and/or a higher power or nature; a sense of meaning in life; and transcendence beyond self, everyday living, and suffering.	Weathers E., McCarthy G. and Coffey A.	2016

The concept of spirituality in relation to the concept of religion

Often when discussing spirituality, the concept of religion also comes to the fore (e.g. Murgia et al. 2020). Therefore, the relationship between these two concepts in the nursing literature will be reviewed.

Originally, in the Western countries, the term 'spirituality' was used in the context of religion (McSherry & Cash 2004). The definition of the concept has changed in recent decades. This has been influenced by the pluralization of many societies. (Murgia et al. 2020.) The concepts of spirituality and religiosity began to diverge in the 20th century. However, the concepts are still strongly linked. (Lazenby 2010; Bruce et al. 2011; Cohen et al. 2012.) In nursing literature, the first concept analysis aiming to distinguish these two concepts has been conducted in the early 1990s. In that analysis, spirituality was seen as an upper concept that could include, among other things, religious elements. (Emblen 1992.)

Oxford English Dictionary (OED 2021) considers spiritual as opposite of worldly or material. Religion, on the other hand, refers to a "particular system of faith and worship" (OED 2021). Religiosity is often associated with a particular religious institution that determines spirituality (Bruce et al. 2011) but a person can be spiritual without being religious (Sessanna et al. 2007; Carr et al. 2011). However, religion strongly influences the concept of spirituality because different religions have their own definitions of spirituality (Johnson et al. 2006).

As religion has been losing its significance due to secularisation, the concept of spirituality has gained more place. Spirituality gives the individual more freedom than religion to determine for himself what exists in addition to the secular and the material. (McSherry & Cash 2004.)

The definition of spirituality in this study

It is recommended that when studying spirituality, researchers clearly state what they mean by the concept in their research (Cohen et al. 2012). Therefore, in this study, spirituality was differentiated from religion, and religiosity was considered as one aspect of spirituality which did not necessarily apply to all people in the same way that spirituality was seen to apply. Spirituality belongs to the inner world of a human and may not be visible to the outside world at all. It contains each person's beliefs and thoughts about the meaning and purpose in and of life. These beliefs and experiences can be influenced by, for example, the surrounding culture or religious environment. Expressing spirituality is voluntary and individual.

Of the previously presented definitions (Table 1), Narayanasamy's (2004, p. 1140) definition describes the use of the concept in this study:

"Spirituality gives us a sense of personhood and individuality. It is the guiding force behind our uniqueness and acts as an inner source of power and energy, which makes us 'tick over' as a person. Spirituality is the inner, intangible dimension that motivates us to be connected with others and our surrounding. It drives us to search for meaning and purpose and establish positive and trusting relationships with others."

In this study, this definition is combined with the view of spirituality as a growth process that can continue to flourish even when physical and cognitive resources are depleted (King 2003, pp. 125-126). The definition considers the fact that spirituality does not end with the aging of a person or the progress of dementia (Jewell 2003, p. 15).

2.2 Review of earlier studies on the phenomenon

In this chapter, supporting the spirituality of older people with dementia will be discussed based on theoretical and empirical literature. The literature review is an update and an extension of the literature review that was conducted in the first phase of this doctoral study (Paper I).

After conducting a narrative literature review as first sub-study of this research on year 2015, in CINAHL, with search phrase [TI spiritual* AND dementia] limited to aged people (65-) altogether 46 results were found (date 19.1.2024). Of them, based on titles and abstracts, 21 were relevant. With the same search criteria, 50 results were found in the PubMed/Medline database (date 16.4.2024). Of them, based on titles and abstracts, 21 were relevant. No new results were found in this search after removing duplicates. The articles based on the three sub-studies of this dissertation were excluded.

2.2.1 Spirituality and people with dementia

In this study, term dementia was used to refer to health problem characterised by progressive memory disorders that affect the cognition. The participating older people in this study had their memory disorder progressed so that they had a diagnosis of dementia. Dementia refers to a syndrome in which cognitive abilities are reduced so that it has an impact on daily life. It can be caused by, for example, Lewy Body disease, vascular disease, or most commonly Alzheimer's disease. (Camicioli 2014.) The disease is progressive and there is no cure for it (MacKinlay & Trevitt 2015).

Many older people fear dementia because they experience it as a self-loss or even as a death before death (Graham et al. 2022). Dementia can cause stress, depression,

anxiety, and loneliness (Beuscher & Grando 2009). Pharmacological cure for dementia is developing but there is a need to find nursing practices and interventions to improve the quality of life of people with dementia. (MacKinlay & Trevitt 2015.)

Spirituality can support coping with a serious illness (Katsuno 2003; Beuscher & Gando 2009). Due to this, supporting spirituality is often seen as a key issue for seriously ill people (Katsuno 2003; Bruce et al. 2011; Carr et al. 2011; Ennis & Kazer 2013). Dementia, as a life-threatening disease, raises existential questions that can leave the person in a spiral search for deeper meaning (Hughes 2020). It has also been noted that an interest in spirituality may increase with aging (Jolley et al. 2010). However, it has been suggested that people with dementia may no longer be able to discuss spirituality since conceptualizing abstract things has become more difficult for them (Dalby et al. 2012). This suggestion may be due to some definitions of spirituality in which cognitive abilities have been considered prerequisites for spirituality (McSherry & Cash 2004).

However, it has also been suggested that older people living with dementia could still engage with and discuss about spirituality (eg. Trevitt & MacKinlay 2004; Beuscer & Grando 2009; Jolley et al. 2010; Carr et al. 2011; Rykkje et al. 2023). Indeed, personal ways of expressing spirituality, such as religious rituals, may persist even with advanced dementia (Hughes 2020) and it has been suggested that dementia can strengthen the spiritual identity (Carr et al. 2011). According to the current understanding, spirituality is not related to cognitive capacity and older people living with dementia may well benefit from supporting spirituality (Beuscher & Grando 2009; Carr et al. 2011).

2.2.2 Spirituality of people with dementia within the context of nursing care

There is a small body of literature that considers supporting spirituality in the nursing care of older people living with dementia. In this chapter, previous research findings that deal with supporting the spirituality of older people with dementia or an environment that supports their spirituality from the perspective of themselves, their family members and nursing professionals, will be presented.

2.2.2.1 Perspective of nursing professionals

In some of the research on the spiritual support, the informants have been nursing professionals (e.g., Carr et al. 2011; Hirakawa et al. 2020). A review has also been conducted to combine knowledge of supporting the spirituality of older people living with dementia from the perspective of healthcare professionals (Camacho-Montaño et al. 2021).

Supporting spirituality has been based on supporting the self-esteem of an older person with dementia (Hirakawa et al. 2020). According to previous research, nursing professionals have used reminiscence of meaningful life events and enjoying small everyday pleasures, to support self-esteem (Hirakawa et al. 2020). Communication has been considered important in supporting spirituality (Hirakawa et al. 2020). Different strategies like active listening have been used in communication (Carr et al. 2011; Hirakawa et al. 2020). Individuality has been emphasized in spiritual support (Hirakawa et al. 2020).

2.2.2.2 Perspective of older people living with dementia and their family members

There are a few studies that consider the lived experience of spirituality support in the nursing care from the perspective of older people with dementia themselves and/or their family members (e.g., Katsuno 2003; Kaufman et al. 2007; Beuscher & Grando 2009; Jolley et al. 2010; MacKinlay & Trevitt 2010; Carr et al. 2011; Dalby et al. 2012; Kirkland et al. 2014; Wu & Koo 2016; Chen et al. 2019; Daly et al. 2019; Mlinar et al. 2021; Britt et al. 2023; McGee et al. 2023; Rykkje et al. 2023). In this chapter, the key results of these studies will be introduced.

Based on the literature, the spirituality of older people with dementia includes a sense of connectedness (e.g. Rykkje et al. 2023), religion (e.g. Chen et al. 2019), a sense of necessity (e.g. Chen et al. 2019) and individuality (e.g. Carr et al. 2011). Spirituality in nursing work is related to caring attitudes (e.g. Mlinar et al. 2021). In the literature, the benefits of (e.g. Carr et al. 2011) and the barriers to (MacKinley & Trevitt 2010) supporting spirituality were detailed.

Sense of connectedness

Connectedness to other people has been found to be an important aspect of spiritual support from the perspective of older people living with dementia (Beuscher & Grando 2009; Dalby et al. 2012; Chen et al. 2019; Britt et al. 2023; Rykkje et al. 2023). Carr et al. (2011) found the central theme in spiritual support to be "little things". They were interviewing older people living with dementia in long term care setting together with their family members, nurses, and hospital chaplains. They stated that spiritual care by recognising these little things promoted sense of connectedness both to self and to other people. (Carr et al. 2011.)

Older people living with dementia have a need to be listened to and to be understood (Dalby et al. 2012). Sense of connectedness could be enhanced for example by supporting participation in spiritual community (Beuscher & Grando 2009; Britt et al. 2023; Carr et al. 2011; Dalby et al. 2012).

Religion

Religion and faith in God have been found to be important for many older people living with dementia (Katsuno 2003; Beuscher & Grando 2009; Carr et al. 2011; Chen et al. 2019). Anyway, church attendance may decrease with dementia. This has suggested to be because social life becomes more difficult as cognition decreases and people with dementia experience shame in social situations. (Katsuno 2003.)

Older people living with dementia have found spiritual routines like bedtime prayer (Beuscher & Grando 2009) particularly comforting (Jolley et al. 2010). Previous research has highlighted, for example, prayer as a spiritual routine that creates a personal connection with God (Katsuno 2003; Beuscher & Grando 2009). Reading the Bible or other scriptures considered sacred has also been mentioned in previous studies, but impaired reading with dementia has also been considered. It may still be possible to listen to familiar texts. (Beuscher & Grando 2009.)

For those for whom religion is an important part of their spirituality, supporting this is essential. To conduct this support, one must find out the spiritual history of the person. (Beuscher & Grando 2009.)

Sense of necessity

The feeling of one's own necessity, the ability to be of help to others, is an important aspect of the spiritual experience of older people with dementia (McGee et al. 2023). It is important to know that not only do older people with dementia need to be helped and supported, but it is also important for them, like for other people, to be there to help and support others (Dalby et al. 2012; Chen et al. 2019; McGee et al. 2023).

Individuality

The individuality of spirituality has been highly emphasized (e.g., Beuscher & Grando 2009; Carr et al. 2011). The starting point for supporting spirituality should always be the older person's own need, not the nursing professional's or caregiver's experience of what is best for the older person living with dementia. (Beuscher & Grando 2009.) Understanding the uniqueness of a person is central to supporting spirituality (Carr et al. 2011).

Caring attitudes

Caring attitudes have been noted to relate to spiritual support in nursing care (Carr et al. 2011; Mlinar et al. 2021). It is about the nurse encountering an older person with dementia as an equal human. (Carr et al. 2011.) Small things that are perceived to support spirituality can be, for example, touching, comforting, being present, and

listening (Carr et al. 2011). Furthermore, it has been found that reminiscence therapy (MacKinlay & Trevitt 2010; Wu & Koo 2016) and music therapy (Kirkland et al. 2014) could improve spiritual well-being of older people with dementia. Additionally, MacKinlay and Trevitt (2010) experienced increased communication among older people living with dementia through regular spiritual remembrance groups.

Benefits of spiritual support

The benefits of considering spirituality in nursing may be reciprocal. Both the nursing professional and the older person with dementia can benefit from it. (MacKinlay & Trevitt 2010; Carr et al. 2011).

In spirituality, an older person living with dementia can find hope, security, and comfort (Katsuno 2003; Beuscher & Grando 2009). Spirituality can increase the sense of belonging (Beuscher & Grando 2009) as well as overall well-being and quality of life (Katsuno 2003). Additionally, a connection has been found between spirituality and slower progression of Alzheimer's disease (Kaufman et al. 2007). Spirituality can reduce depression (Katsuno 2003).

Facilitators and barriers to spiritual support

There are some facilitators and barriers to supporting spirituality of older people with dementia, regarding for example time resources and competence of the nursing professionals. Also, not all professionals believe that people with cognitive decline are capable of the depth that spirituality requires. (MacKinlay & Trevitt 2010.)

2.2.3 Caring and living environment that supports spirituality

Attention has been paid to the effects of the nursing environment on improvement of well-being since the early days of professional nursing (Rogers 1988; Newman 1992; Rogers 1992; Biley & Freshwater 1998). In this study, the nursing environment is referred to with the concept 'caring and living environment'. The term refers to a space where older people with dementia are cared for and where they live there own individual life.

In nursing theories there are different ways of conceptualizing and understanding environment (Kim 2010, pp. 219-266). In Kim's (1992) typology structuring nursing knowledge the fourth domain is environmental. Kim (2010, pp 220) explains that environment is an essential part of being human in the world. In the typology, the environment is divided to spatial, temporal, and qualitative aspects that affect to people in different ways and intensities. The physical, social, and symbolic

qualitative characteristics of the environment are seen as separate phenomena. (Kim 2010, pp. 219-266.) This theoretical conceptualization was used to understand the caring and living environment in this research.

In the light of this typology, spirituality can be seen to be tied to all three qualitative characteristics of the environment (see Kim 2010, pp. 228). However, above all, spirituality is part of the symbolic environment. Spirituality is included in the invisible world that exists in people's minds but also manifests itself through the social and physical environment. Spirituality, as a highly individual-specific phenomenon, cannot be objectively observed in the environment. (see Kim 2010, pp. 223-224.)

In recent decades, efforts have been made to domesticate institutional care environments with the aim of improving the quality of life of people with dementia (Dröes et al. 2006). According to Chaudhury et al. (2017) older people with dementia can benefit from the physical environment in many ways. There are possibilities to maximize safety, support cognition and physical abilities and enable social connections as well as provide privacy (Chaudhury et al. 2017).

When moving to the connections between the environment and spirituality, Biley and Freshwater (1998, p. 98) noted in the late 1990s:

"It could be argued that juxtaposing the spirit and the environment is creating a false relationship. However, when the relationship between the place in which we live, the places in which we are cared for is fully explored, then the interrelationship with the spiritual dimension emerges and becomes more significant."

Vitorino et al. (2019) examined in their study associations between aspects of physical environment and spiritual coping behaviours in Brazil. The target group of their study was older people, who were not mentioned as having dementia. They were examining associations between physical environment and spiritual coping. They came into a conclusion that physical environment influences spiritual coping and should therefore be considered in older people nursing. (Vitorino et al. 2019.)

2.3 Gaps in the knowledge of current literature

In this chapter, the gaps in the knowledge of supporting the spirituality of older people living with dementia in their caring and living environments will be summarized. The literature review clearly points out the little amount of evidence and focus on supporting the spirituality of older people with dementia in their caring and living environments.

In summary, it has been noted that the spiritual needs of older people with dementia are often neglected in nursing care (Daly et al. 2014; Chen et al. 2019). The spirituality of older people with dementia has been studied rarely in the context of nursing, from the perspective of nursing professionals, older people with dementia and their family members. The perspective of family members of people with dementia in supporting the spirituality of a person with dementia has been researched marginally, even though the family members' own coping with the help of spirituality has been studied to some extent (e.g., Britt et al. 2023).

Spirituality in caring and living environments has hardly been studied. The environment that supports the spirituality of older people with dementia has not, to my understanding, been studied before using these concepts. The studies were searched for with several different keywords in different databases, but no such studies were found. However, environment is a component included in the paradigm of nursing science (Conway 1985), where people live and with which people constantly interact (Kim 2010, p. 220). This perspective is central to supporting the well-being of older people with dementia. The environment refers to a physical, social and symbolic entity (Kim 2010, p. 220). Spirituality can manifest in the physical and social environment, but symbolism is always central to spirituality in the environment, because through symbolism people create spiritual meanings for their physical and social environment.

Spirituality is a culturally sensitive area (Murgia et al. 2020), so exploring it in different cultural environments is important (Britt et al. 2023). The target groups of this study were nursing professionals working in older people care in Finland, as well as older people with dementia and their family members who lived in Finland. The phenomenon had not been studied in Finnish context before.

Ennis and Kazer (2013) highlighted that there is a need to improve understanding of dementia and spirituality. Carr et al. (2011) stated the same as they concluded that there is a need to study phenomenon in different settings. And if we are to better understand the experiences of older people living with dementia it is important to involve themselves in the research (Mmako et al. 2020). Dalby et al. (2012) suggested also including family members of older people living with dementia in future research.

There are theories of spirituality (see e.g. Carroll 2001) but no models or theories aiming to understand supporting the spirituality of older people with dementia in their caring and living environment. In summary, there is a gap in nursing research on supporting the spirituality of older people with dementia (Mlinar et al. 2021; Rykkje et al. 2023).

3 Aims of the Study

The overall aim of this study was to achieve a comprehensive understanding of supporting the spirituality of older people living with dementia in their caring and living environments (Figure 3). The study included two phases, a descriptive phase and an analytic phase (Figure 4).

The sub-aims and research questions (RQ) were as follows:

Descriptive phase: The aim was to describe and understand how spirituality of older people living with dementia can be supported in their caring and living environment.

- RQ1: How spirituality has been supported in the nursing care of older people living with dementia in earlier literature?
- RQ2: What are the lived experiences of nursing professionals on supporting the spirituality of older people living with dementia?
- RQ3: What are the lived experiences of older people with dementia and their family members of spiritual support in nursing care?

Analytic phase: The aim was to analyse which elements in the caring and living environment of older people living with dementia support their spirituality. In the analytic phase, the aim was also to compile the results of the sub studies to form a descriptive theory of the phenomenon.

RQ4: Which elements in the caring and living environment support the spirituality of older people living with dementia experienced by themselves and their family members?



Figure 3. Research questions and study designs.

The purpose was to achieve a holistic understanding of supporting the spirituality of older people living with dementia in their caring and living environments.

Phase I DESCRIPTIVE PHASE

Aim: To describe and understand supporting the spirituality of older people living with dementia in their caring and living environment.

Sub-study 1: Literature review (Paper I)

Aim: To describe how has spirituality been supported in the nursing care of older people living with dementia in existing literature?

Design: Narrative literature review

Sample: 10 scientific articles

Sub-study 2: Qualitative study (Paper II)

Aim: To understand and describe what are the lived experiences of nursing professionals on supporting the spirituality of older people with dementia?

Design: Hermeneutic phenomenological interview study

Sample: Nursing professionals (n=17)

Sub-study 3: Qualitative study (Paper III)

Aim: To understand how older people living with dementia and their family members experience spirituality and its support in nursing care.

Design: A qualitative study informed by the principles of Ricoeurian hermeneutic phenomenology.

Sample: Older people with dementia (n=10) and their family members (n=9).

Phase II ANALYTIC PHASE

Aim: To analyse which elements in the caring and living environment of older people living with dementia support their spirituality.

Sub-study 4: Qualitative study (paper IV)

Aim: To further understand the spirituality-supportive elements of a caring and living environment from the perspective of older people with dementia and their family members.

Design: Hermeneutic-phenomenological interview study utilizing photoelicitation as a visual method to collect data.

Sample: Older people with dementia (n=10) and their family members (n=9).

Figure 4. Study Phases and Sub-Studies.

4 Materials and Methods

This two-phased study, based on hermeneutic-phenomenological philosophy, was conducted in the context of home care and long-term care settings among older people with dementia in urban and suburban areas around one medium-sized town in southwestern Finland. The data were collected between 2014 and 2020.

In phase I, the aim was to describe how spirituality of older people living with dementia can be supported in their caring and living environments. In phase II, the aim was to analyse which elements in the caring and living environment of older people living with dementia support their spirituality. Based on this analysis, the aim was to analytically compile the results of the sub studies to form a descriptive theory of the phenomenon. Various materials and methods (Table 2) were utilized to answer the research questions.

Table 2. Phases, research questions, designs, samples, data collection and analysis of substudies.

PHASE	RQ	SUB- STUDY	DESIGN	SAMPLE	DATA COLLECTION	ANALYSIS	PAPER
DESCRPITIVE	1	I	Narrative literature review	Research articles (n=10)	Systematic literature search	Inductive content analysis	Paper I
DESCRIPTIVE	2	II	Heideggerian hermeneutic phenomenology	Nursing professionals (n=17)	Unstructured individual interviews	Inductive content analysis	Paper II
DESCRIPTIVE	3	III	Ricoeurian hermeneutic phenomenology	, , ,	In-depth interviews in dyads or individually	Ricoeur's theory of interpretation	Paper III
ANALYTIC	4	IV	Hermeneutic phenomenology	their family members (n=9)	In-depth interviews in dyads or individually, photo- elicitation	Thematic interpretation	Paper IV and the summary

In a narrative literature review (Paper I), the research question was how the spirituality of older people living with dementia has been supported in nursing care in earlier research. Based on the literature review, it was found necessary to explore

the phenomenon further from the perspective of nursing professionals (Paper II) and from the perspective of older people living with dementia as well as their family members (Paper III).

Since the intention was to study the support of spirituality specifically in the context of nursing, nursing professionals were those who were considered to have lived experiences of the phenomenon (see Van Manen 1990, pp 35-51). People with dementia have often been excluded from qualitative research (Diaz-Gil et al. 2023) even though they are in a central position in matters related to their own care (Kowe et al. 2022). Their family members often play a key role as advocates for people with dementia as the disease progresses (Reid & O'Brien 2021). However, the views of family members on supporting the spirituality of older people with dementia have been little studied as revealed in the literature review. Therefore, ways to understand the phenomenon were considered from the perspectives of these three groups of participants.

The participants' experiences were discovered by interviewing them individually or in pairs. Interviews of nursing professionals were carried out as individual interviews, while older people with dementia were interviewed in pairs together with their family members. This makes it easier for people with dementia to participate in interview studies (Morgan et al. 2013).

The caring and living environment that supports spirituality was studied from the perspective of older people with dementia and their family members (Paper IV). It was their lived experiences that was seen as important to understand the phenomenon, because they were seen as stakeholders, as experiencers of the environment. They were people who lived in the environment, while nursing professionals were seen more like visitors to the caring and living environment of older people with dementia. (See Lindseth & Norberg 2022.)

The interviews were conducted in the caring and living environment of a person with dementia (see Beuscher & Grando 2009). Since the physical environment contains elements of spirituality through symbolism (Petersson et al. 2016), expressing it only verbally could be challenging (Ryan et al. 2005). Therefore, photography was utilized in this phase of the study (see Chen et al. 2022).

Referring to the previous reflection on spirituality being individual phenomenon (Ødbehr et al. 2017), a qualitative approach was chosen. Spirituality is a highly emotional and subjective phenomenon, so qualitative approach was considered to value the participants' lived experiences. (Holloway 2017, pp 12-14.)

Qualitative approach to research is understood like Denzin and Lincoln (2005) define it:

"Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of

representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. (2005, p. 3.)"

In qualitative paradigm there is an aim to describe, understand and interpret (Charalambous et al. 2008; Curtis & Keeler 2022). These aims were pursued through different hermeneutic phenomenological approaches. Hermeneutic phenomenology belongs to the interpretive tradition within phenomenology (Tuohy et al. 2013), and the interpretive approach was used in the analyzes of the data. In this chapter it will be explained how these qualitative approaches of hermeneutic phenomenology were chosen to answer the research questions. (see Crowther & Thomson 2022.)

4.1 Study design

4.1.1 Narrative literature review

A narrative literature review was conducted to describe how spirituality has been supported in the nursing care of older people living with dementia in earlier research and literature (Paper I). Spirituality as a phenomenon is abstract and culturally bound (Murgia et al. 2020), which was sought to understand in the light of previous research through the narrative review (see Kangasniemi et al. 2013). The type of review was chosen for a little-researched phenomenon to get an overview of the published information related to the phenomenon (Sataloff et al. 2021).

Before starting the actual review, preliminary searches were made in the databases to determine the search terms (Green et al. 2006). The review was conducted as described by Kangasniemi et al. (2013, Figure 5). First, the research question was formulated. The research question was: "How can spirituality be supported in the nursing care of older people with dementia?" The aim was also to find out the gaps in existing research. Secondly, the data was selected. The literature was searched systematically in two relevant databases, CINAHL and PubMed, in the beginning of the year 2013. Thirdly, inductive qualitative content analysis was used to construct the description (see Graneheim & Lundman 2004). Finally, the results were observed mirroring them to the researcher's preconceptions and general literature on the phenomenon. Based on the results, conclusions were drawn. The steps did not proceed in order but circumferentially back and forth. (Kangasniemi et al. 2013.) For the summary, the literature review was updated and supplemented in the chapter 2.

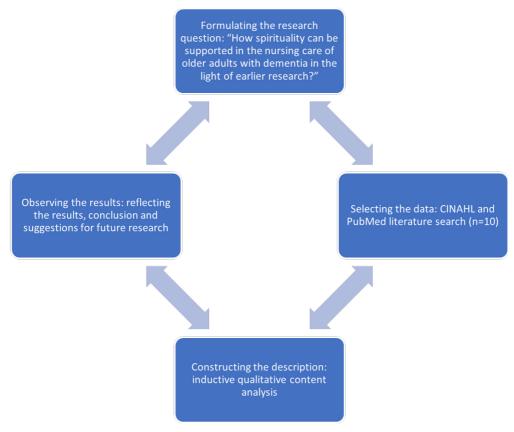


Figure 5. The circle of the narrative literature review (see Kangasniemi et al. 2013).

4.1.2 Hermeneutic phenomenology

Hermeneutic phenomenology was the background philosophy throughout the study. Until the 1970s, hermeneutics referred mainly to theology and the interpretation of texts, but gradually it gained more room in the social sciences. Hermeneutic philosophy sought to understand and learn from human experiences. The perspective on hermeneutics is interpretive, meaning it focuses on understanding behind explicit expression. (Thompson 1990.) In hermeneutic phenomenology, person is seen as constantly interacting with the living environment creating meanings and interpretations of the phenomena (Charalambous 2014). This interaction with the environment was emphasized in this study.

Therefore, hermeneutics is a way of understanding another person's experiences (James & Komnenich 2021) and this perspective of understanding was needed when considering how to research spirituality. Thus, the roots of hermeneutics lie in the interpretation of religious texts (Thompson 1990), and even after expanding beyond religion (Lazenby 2010), spirituality as a phenomenon needs an interpretation

(Clarke 2006), a hermeneutic circle through which the individual experiences of others can be understood (James & Komnenich 2021).

Phenomenology was first established by Edmund Husserl (1859-1938) (Lindseth & Norberg 2022). Husserlian descriptive phenomenology (Dowling & Cooney 2012) seeks to capture the phenomenon as such, to find the 'thingness of the thing'. In hermeneutic phenomenology, the phenomenon is approached in the hermeneutic circle alternately from the whole of the phenomenon to the parts and back. (Ranse et al. 2020.) Hermeneutic phenomenology was chosen as the background philosophy and research method of the study to understand the phenomenon of spirituality through the participants' own lived experiences (see Morse 1991). In this study, the phenomenon was named 'supporting the spirituality of older people with dementia in their caring and living environments'.

Heideggerian approach to hermeneutic phenomenology (see e.g. Dowling & Cooney 2012) was chosen to examine the lived experiences of nursing professionals. Heidegger was a German philosopher (Cooper 2001, p 1.) who added an interpretive dimension to phenomenology and to understanding of the phenomenon (James & Komnenich 2021). This interpretation was considered necessary in the study of nursing professionals' experiences. Heideggerian phenomenology has been used widely in nursing research to study lived experiences by interviewing people who have experienced the phenomenon themselves (Gullick & West 2020). However, this has also been criticized because Heidegger himself did not talk about lived experiences (Paley 2014).

Ricoeurian hermeneutic phenomenology (see e.g. Geanellos 2000) was adapted to interpret lived experiences of older people living with dementia and their family members. According to Ricoeur (Reagan 1996, pp. 100-109), hermeneutics and interpretation are inextricably linked. In Ricoeurian hermeneutics it is not about understanding the narrator but concentrating on the text. However, it is about more than just describing the text as it is. Through describing the content of the text, Ricoeur sought to gain a deep understanding by moving from what the text says to what it actually talks about. (Charalambous et al. 2008.)

The conceptualization of hermeneutics is not quite simple, but requires a deeper understanding: What is meant by the true 'thing' of the text (Charalambous et al. 2008) or the 'world of the text (Ricoeur 1981, pp. 140-142)'? What does 'being-in-the-world (Svenaeus 2011)' mean? Husserl used expression *Lebenswelt* which means 'life-world' and Heidegger was talking about 'being-in-the-world' (Svenaeus 2011). With these expressions they both referred to same phenomenon that is central in hermeneutics: what is inside the text considering the author, context, and the text itself (Geanellos 1998).

Ricoeur was talking about 'the world of the text' (Ricoeur 1981, pp. 140-142.) and Gadamer about 'die Sache', 'the matter of the text' (Charalambous et al. 2008).

Nevertheless, there are nuances in these concepts. In this study, the aim was to understand the *life-world* in which older people with dementia experience spiritual support; to understand how they truly live their experience of spiritual support in their world [being-in-the-world] based on interviews written in text [world of the text].

In phenomenology and hermeneutic phenomenology, it is important for a researcher to be aware of own preunderstanding of the phenomenon (Dodgson 2019). The aim in this study was to understand the experiences of the participants. That is why I considered and expressed my own preunderstanding before starting the interviews (see e.g. Spence 2017).

My preunderstanding of the phenomenon

The researcher's own cultural and religious background can possibly affect the way of understanding spirituality (Best et al. 2022). The intention in expressing my preunderstanding and explaining my own background related to spirituality is that the reader can mirror the study results in the researcher's world of experience and take it into account possibly influencing on the results (Olmos-Vega et al. 2023).

I completed the first practical training of my nursing studies in a long-term care department for older people with advanced dementia. It was new to me to find out that there were so many older people with dementia that had progressed so far that they were no longer able to move independently or to communicate verbally. I felt a need to bring into their life some glimpses of light and experiences of connection with another people.

As a registered nurse, I continued working in dementia care for older people. After starting my master's studies, I read about supporting spirituality in nursing care. I had always been interested in different cultures, religions, and philosophies of life, so I became interested in the topic, and thought this could be one way to enhance the quality of life of older people living with dementia.

I believe spirituality refers to those things that transcend humanity. I understand spirituality to refer to religions or other philosophies of life that somehow connect the person with what is sacred in life. So, I think that a person who is not religious, can still be spiritual.

I have lived in a Christian Finnish culture almost all my life except living for three years in Jewish Israel. I have never been a member of any religious church or community. Nevertheless, I am particularly interested in religions and belief-systems as well as not believing and other philosophies of life. I believe that the consideration of spirituality is an important part of nursing care because it might give people hope in difficult life situations.

4.2 Setting, sampling and sample

4.2.1 Setting

As explained before, for understanding spirituality, it is important to consider cultural and religious context (Vieten & Lukoff 2022). The data collection was conducted in urban and sub-urban area of Southern Finland.

In Finland, most of the people belong to Christian churches (Statista 2021). Most of them belong to the Evangelical Lutheran Church, whose membership has decreased, but still covers about 70% of the Finnish population. In addition, there are several other Christian denominations and other religious communities in Finland, such as Islam and Judaism. (Infofinland 2022.) There is also a growing population who are not members of any religious communities (Statista 2021) and secularization has taken place within religions (Idler 2022). The trend is in line with the rest of Europe and the Americas, i.e., the decline in religious participation as generations change (Idler 2022).

4.2.2 Description of the participants

The study was conducted in both long term and home care settings of older people living with dementia in Finland. The nursing care of older people with dementia in both settings was organized by municipal, private or third sector. In long term care, older people with dementia were living in their own private rooms. In home care, older people with dementia were living in their own homes cared by nursing professionals. The environments in different settings varied but the phenomenon of supporting the spirituality of older people with dementia appeared in all care settings.

In total, 17 nursing professionals, 10 older people living with dementia and 9 of their family members were recruited for this research. They represented the Finnish cultural and religious background. Some nursing professionals were immigrants, which is also a part of contemporary Western multiculturalism (Ham 2021). Most participants were members of the Evangelical Lutheran Church. For some of them, religion was an important part of life, but for most, it was of only minor importance. The atheistic philosophy was also represented.

In the first sub-study (Paper I), the data consisted of the literature on the phenomenon (n=10). An electronic search for relevant published literature was conducted using international CINAHL and MEDLINE (PubMed) databases. The articles included in the review were from Australia, Canada, United Kingdom and United States from years 2005-2012.

In the second sub-study (Paper II), 17 nursing professionals were recruited for interviews. Nursing professionals (n=17) were working in home care or long-term

care settings in the private, municipal or third sector. They were expected to have at least one year's experience of the nursing care of older people with dementia so that they could discuss the phenomenon based on their own lived experiences (e.g. Bynum & Varpio 2018). Their age varied from 28 to 68. All of them were female.

In the third and fourth sub-studies (Papers III and IV), older people with dementia and their family members were interviewed. In the fourth sub-study (Paper IV) the same group participated also in photo-elicitation. Older people with dementia (n=10) were clients of either home care or long-term care. Their age varied from 76 to 97. Of them, 7 were female and 3 were male. Five were diagnosed with Alzheimer's disease and four with other types of dementias.

Their family members (n=9) were individuals who were actively involved in the life of an older person with dementia and were aware of their nursing care. Their age varied from 45 to 80. Of them, 7 were female and 2 were male.

4.2.3 Data collection

For the literature review, the data were collected by electronic search in two international databases. The search for literature was conducted systematically by using inclusion criteria (Table 3).

Table 3. The inclusion criteria.

LITERATURE	NURSING PROFESSIONALS	OLDER PEOPLE WITH DEMENTIA	FAMILY MEMBERS
Studies involving adults 65 years or older	Being a registered nurse or an assistant nurse	Adults 65 years of age or older	Being familiar with the nursing care of older person living with dementia
Published in English	Have at least 1 year's working experience in the nursing care of older people with dementia	Ability to express oneself verbally	Older person with dementia agrees that the family member participates
Focusing on nursing care carried out by nursing professionals	Willingness to participate in the study	Diagnosed with dementia	Willingness to participate in the study
If the mini-mental state examination score was mentioned the upper limit of dementia was 23 points		Ability to give consent and having a proxy who can confirm the consent	
Any term referring to spirituality in the title		Being a home care client or living in nursing home	
		Willingness to participate in the study	

In hermeneutic phenomenology, the data collection method is not specified (Charalambous & Charalambous 2016). However, in hermeneutic phenomenology, for example, Heidegger (2014, pp. 56-58) emphasized the importance of conversation as the basis of being human. Based on this, interviewing was considered a suitable method to capture the lived experiences. In the three qualitative sub-studies, purposive sampling was used for data collection to find participants who had personal experience of the phenomenon. (Campbell et al. 2020.) For the second sub-study, data were collected by interviewing a purposive sample of 17 nurses (Paper II). For the third sub-study, the data were collected from a purposive sample of 10 older people living with dementia and their 9 family members (n=19) (Paper III). The data were collected at the same time for third and fourth sub-studies because the target group was the same. For the fourth sub-study, the data collected by interviewing was supplemented with photo-elicitation (Paper IV) to facilitate vulnerable group in expressing their lived experiences on phenomenon that might be challenging to put into words (Bugos et al. 2014).

Altogether 36 individuals were interviewed to conduct this study and altogether 75 photographs were taken during the research. The inclusion criteria are presented in table 3.

Data management

The data collected for this research project consisted of recorded interview data, transcribed manuscripts (in Word files), and photographs. Also, field notes were used to document contextual information (Phillippi & Lauderdale 2018). The field notes were saved with date, context, and setting.

The consistency and quality of recorded interview data was assured by locating the recorder near to interviewees and by checking the quality of recording in the beginning of each interview. The recordings were saved electronically straight after each interview. They were transferred from the recorder to a password-protected folder on the researcher's computer. The recordings were immediately removed from the recorder. Participant details were saved separately in table form. The photographs were saved in the highest possible resolution to make it possible to use them in publications.

The data included sensitive information and could not be made open. If someone wanted to use the raw data, it must be requested privately from the researcher. The data consists of very sensitive stories of people. They discussed a lot about their religious views and supernatural experiences. This must be considered when thinking about reusing the data by other projects. In informed consent form, it was assured that the anonymity of the participants will be secured. They permitted that their interviews can be used in scientific research and published as such.

4.2.3.1 Interviews

The interviews with the nurses ranged from 36 to 74 min and with older people with dementia and their family members from 56 to 110 min. All interviews were conducted by the researcher who has a background of working as a registered nurse in older people care. The interviews were recorded and transcribed verbatim by the researcher. The third party was not used because of the transcribing was seen as a good way to get familiar with the data (Aveyard & Schofield 2002).

Nursing professionals were interviewed in their working units. Each participant was interviewed individually. The starting question was: 'What experiences do you have of spirituality in the care of older people with dementia?'

Older people living with dementia were mainly interviewed as dyads together with their family members either in their own home or private room if living in a nursing home. Conducting interviews in own homes of people with dementia has been found to make it easier for older people with dementia to participate in interview studies (Clarke & Keady 2002, p. 34; Karlawish et al. 2008). Dyadic interviewing is an interactive interviewing technique. In dyadic interview, two participants interact with each other and with the interviewer to answer open-ended interview questions. (Morgan et al. 2013; Taylor et al. 2021.) In this study, one person with dementia was interviewed individually without a family member. There are some advantages in interviewing people with dementia together with their family members. It has been assumed that people with dementia might feel more comfortable in interviews with their family members. (Pratt 2001.)

Due to the subjective nature of the experience of spirituality (Rykkje et al 2023), an interview guide was not used in interviewing the dyads. Instead, the participants were invited to speak openly about their experiences of supporting the spirituality of older people with dementia and about the caring and living environment that supports spirituality.

When considering an environment that supported spirituality, it was realized that verbal expression of it might not be sufficient. Photo-elicitation was utilized to supplement verbal expression. (See Phillipson & Hammond 2018.)

The sample size was determined by data saturation. There are different variants of saturation. The one that was used in three original publications (Paper II, III and IV) was inductive thematic saturation. (Leese et al. 2021.) In the second sub-study (Paper II) the saturation was based on codes but in the third (Paper III) and fourth (Paper IV) sub-studies on meanings as both Ricoeur's interpretation theory and inductive thematic content analysis aim to deep interpretive understanding of the data (Hennink et al. 2017). Practically, the evaluation of saturation was conducted in the steps adapted from Buckley (2022, Table 4).

Table 4.	Steps of the evaluation of saturation	(see Buckley 2022).
----------	---------------------------------------	---------------------

Step	
1	The framework was defined by conducting a literature review (Paper I).
2	The target class was specified for each group of participants: older people with dementia, their family members and nursing professionals.
3	Inclusion criteria were written down for each group of participants (Table 3).
4	To minimise selection bias, all willing candidates meeting the inclusion criteria were included in the study.
5	Sufficient heterogeneity of the participants was reported by describing the participant information.
6	The data was comprehensively coded.
7	Code saturation was selected for the second sub-study and meaning saturation for the third and the fourth sub-studies.
8	Thematic level of saturation was specified to be sufficient within the phenomenon full of varying nuances.
9	Participants were interviewed in the order they contacted the researcher and reported in the order they were interviewed. The saturation path can be followed based on this.
10	The saturation was reached when new themes did not emerge in the two last interviews.

Complexity of the researched phenomenon can have an influence on saturation (Squires & Dorsen 2018). Spirituality as a complex phenomenon (Ennis & Kazer 2013) has a wide variety of nuances that cannot all be captured. Therefore, the saturation was based on large entities.

4.2.3.2 Photography

In this study (Paper IV), photo-elicitation was utilized to help participating older people with dementia and their family members to identify the spirituality-supportive elements of the caring and living environments of older people living with dementia. Photo-elicitation is a qualitative research technique first invented in 1957 utilizing photography or photos in interviews (Bugos et al. 2014).

Various photographic methods have been used in research on older people with dementia and their environment (e.g. Seetharaman et al. 2021; Gibson et al. 2022). Dyadic interviews and photography have been combined in dementia study earlier by Morgan et al. (2013).

In photo-elicitation method, the participants usually take the photos by themselves after experiencing a phenomenon that the researcher wants them to illustrate (Bugos et al. 2014). Photography has been found to benefit people with cognitive impairment to express their experiences. (Renn et al. 2021.)

In this study (Paper IV), photo-elicitation was adapted to fit together with the purpose and the participants of the study (see Conway et al. 2023). Professional photographer was present in the interview settings from the beginning listening to conversations concentrating on what the participants were talking about the environment that supported spirituality. In each interview, the researcher requested the participants to show which elements in the living and caring environment of older people with dementia would they photograph if they were to express spirituality supportive environment by photos. The photographer took the photos of all the elements the participants were talking about. At the same time, the researcher continued discussing with participants and asking more about the elements they chose to be photographed in their environment.

Therefore, photo-elicitation was used to prompt in-depth interviews (Bugos et al. 2014). The professional photographer was utilized since it has been noted in earlier studies that older people with dementia might find photographing technically challenging (Seetharaman et al. 2021).

The idea in photographing the environment was that the elements in the environment that support spirituality could be challenging to capture merely verbally (Murgia et al.2022). It was essential to approach the environment as an entity that could be visually captured in photographing together with verbal expression. Photos alone did not narrate the lived experiences of older people with dementia and their family members. They were used to lead the participants to versatile and rich expression of the phenomenon. (Paper IV.)

4.3 Data analysis and interpretation

In this chapter, the methodological choices to analyse the data for the literature review and interpret the qualitative data, will be introduced. The data were collected by interviewing older people living with dementia, their family members and nursing professionals as well as by photographing. Three different ways of interpreting the qualitative data were used. In each phase, the interpretation process was conducted simultaneously with the data collection as typical in qualitative research (Merriam & Tisdell 2015, pp 195).

4.3.1 Descriptive phase

4.3.1.1 Qualitative inductive content analysis

Graneheim and Lundman's (2004) conceptualisation was used in defining the stages of the qualitative content analysis and the use of concepts in the first and second substudies. In the first sub-study, qualitative inductive data analysis was used to analyse

existing literature (Paper I) and in the second sub-study, to analyse lived experiences of nursing professionals (Paper II). As was explained before, there is no consensus on defining spirituality in nursing care (Murgia 2020). That is why the data analysis was conducted inductively to describe supporting the spirituality in the light of the literature and to understand the experiences of nurses supporting the spirituality of older people living with dementia.

What distinguished the analysis of the second sub-study from the inductive qualitative analysis of the literature review (Paper I) was the interpretive dimension (Bynum & Varpio 2018), where attention was paid to the latent meaning of the data in addition to the manifest content. Field notes and research diary were used to start with the analysis from the beginning of the data collection. This made the final intensive analysis easier and made it possible to decide when the saturation was achieved within coding. (Merriam & Tisdell 2015, pp 195-199.) The circular analysis process, which was carried out simultaneously with the data collection, is described in Figure 6.

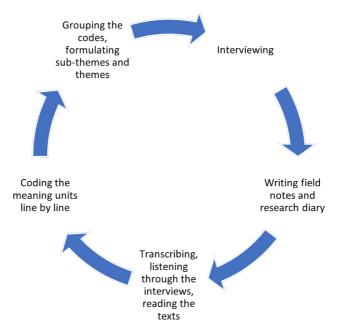


Figure 6. Qualitative inductive data analysis conducted in step 2 (Paper II, see Graneheim & Lundman 2004).

Coding was conducted by collecting meaning units from the transcribed text and condensing them. The codes were derived from the condensed meaning units. (Table 5.) Codes were then grouped, and subthemes and themes were created based on them. (Graneheim & Lundman 2004.)

Table 5.	An example of meaning units, condensed meaning units and codes (see Graneheim &
	Lundman 2004).

Meaning unit	Condensed meaning unit	Code	
Not listening to the words only but hearing the person.	Listening what the person wants to tell	Active listening	
I was sitting next to her, there on her bed and she was holding my hands and then she started to pray there.	She started to pray	Praying	

4.3.1.2 Ricoeur's theory of interpretation

Ricoeur's theory of interpretation was chosen for philosophical background and as a way of interpreting the lived experiences of older people living with dementia and their family members in the third sub-study (Paper III). Ricoeur's interpretation theory was first introduced to the researcher by Charalambous who had been using it as a way of interpreting the data in qualitative studies (e.g., Charalambous et al. 2008; Charalambous et al. 2009; Charalambous & Kaite 2013; Charalambous 2014; Charalambous & Charalambous 2016). Paul Ricoeur was a French philosopher (Charalambous et al. 2009) who has been writing for example about philosophy of the will, psychoanalysis and structuralism, theory of the text and about educational and theological issues (Thompson 1981, pp. 1).

The philosophical background of the theory was considered appropriate for spirituality as a phenomenon. In Ricoeur's theory, the whole person is considered. The culture, world of beliefs and values of both the researcher and the participants are understood. (Charalambous et al. 2008.) These three are central to the study of spirituality.

In this study, the data consisted of transcribed interviews aiming to understand how older people with dementia and their family members experienced spiritual support in the living ang caring environments of older people with dementia. Spirituality was seen as a part of symbolic living and caring environment (Kim 2010, pp. 235-238). Ricoeur, in his early work concentrated on interpreting the symbols. From that, he expanded to the interpretation of discourse. However, in his interpretation theory the meanings of symbols have their role. (Charalambous et al. 2008.) His theory was seen as a steady basis to study spirituality expressed through symbolic language.

Ricoeur did not build his profound theory to be a method for interpreting qualitative research data (Hardwick 2017). However, as such, it brought a deep understanding of the phenomenon studied but needed concentration and thinking it through. For achieving comprehensive understanding of the phenomenon,

philosophical consideration of each step was needed. Understanding about the philosophy and theory and even the person behind it, was needed. Without this understanding, it would have not differed from other qualitative techniques for data analysis. But when understanding the theory behind the method, the method came alive and helped to dive deep in the data; into the experiences of the people that were interviewed. (See Wiklund et al. 2002; Charalambous et al. 2008.) First conducting the naïve reading and then working towards the comprehensive understanding through structural analysis with understanding of the philosophy behind it, Ricoeur's theory offered an efficient way of interpreting the data (see Wiklund et al. 2002).

Ricoeur had an intention to benefit from both romantic hermeneutics that aimed to capture the soul of the author from the text and structuralist hermeneutics that concentrated on the manifest content of the text chopping it on the small pieces. (Ricoeur 1981, pp. 140-142.) On this basis, his theory was very useful in interpreting qualitative data when there was a need for understanding the lived experiences (Charalambous et al. 2008).

The steps of the interpretation process modified by Lindseth and Norberg (2004), naïve reading, structural analysis, and comprehensive understanding, capture the idea of Ricoeur's theory of interpretation. This three-step process was used in this study to interpret older people's and their family members' lived experiences. Comprehensive understanding was achieved by going through these steps back and forth. Interpretation was a circular process (hermeneutic circle). (Charalambous & Charalambous 2016.) As Ricoeur puts it: "to interpret is to explicate the type of being-in-the-world unfolded in front of the text (Ricoeur 1981, pp. 141)." Starting with naïve reading, 'what the text says', the interpretation moved through structural analysis to comprehensive understanding, 'what the text talks about', (Ricoeur 1976, pp.87-88; Ricoeur 1981, p. 163) what is the 'world of the text' (Charalambous et al. 2008).

Concretely, naïve reading meant listening through the recordings and reading through the transcribed texts to get an overall picture of what the participants were saying. This was written down. (Wiklund et al. 2002; Simonÿ et al. 2018.) Structural analysis was conducted as a qualitative coding process collecting meaning units of the text and grouping them into sub-themes and themes (Lindseth & Norberg 2004). As typical in Ricoeur's theory of interpretation, the basic message of the text revealed in naïve reading, was used as a framework for structural analysis. The new aspects on the phenomenon found in structural analysis were utilized to re-formulate naïve reading. (Charalambous 2014.) To achieve comprehensive understanding on the phenomenon based on the lived experiences of the participants, the researchers' preunderstanding and knowledge of earlier literature was combined with the findings of the naïve reading and the structural analysis (Lindseth & Norberg 2004; Charalambous 2014). (Table 6.)

Table 6. Process of interpretation.

Phase of the interpretation		What was concretely done	
1.	Naïve reading	Familiarization with the data by listening to the recordings and reading the texts. Writing a short description of what the text says.	
2.	Structural analysis	Collecting meaning units, coding, categorizing based on the description revealed in naïve reading.	
3.	Comprehensive understanding	Reflecting the findings of naïve reading and structural analysis in the light of researchers' pre-understanding and earlier literature.	
		Deepening the interpretation and writing a comprehensive understanding of the phenomenon.	

Two essential ideas in Ricoeur's theory are 'distanciation' and 'appropriation'. Distanciation means that we are aware of our own preunderstanding about the phenomenon we are researching. Based on this awareness, we can distance ourselves from our own presuppositions and appropriate the new understanding about the world. (Charalambous et al. 2008.)

4.3.2 Analytic phase: Inductive thematic content analysis including photo-analysis

Inductive thematic content analysis was utilized to understand the spirituality-supportive living and caring environment of older people living with dementia (Paper IV). For inductive thematic analysis, several different ways of concretely doing analysis and interpretation can be used (Guest et al. 2012). In this study, the thematic analysis introduced by Clarke and Braun (2006) was adapted to interpret the data.

Thematic analysis is a flexible method not demanding any specific theoretical background (Clarke & Braun 2017). It can be conducted within hermeneutic-phenomenological framework in interpretive way as in this study. The aim was to capture participants' lived experiences of the phenomenon. (Ho et al. 2017.)

The interpretation included six steps (Clarke & Braun 2006). First, the researcher was familiarized with the data simultaneously with transcription and by reading transcribed texts and reviewing the photos while writing notes. Secondly, all expressions relevant to the research question, i.e., codes, were collected. Each photograph was also seen as a code. Thirdly, the text codes and photographs were organized into groups where they formed sub-themes, and these formed larger themes (Table 7). Next, the themes were reviewed on two levels: in relation to the codes and the data. Fifth step was to define and reconsider the names of the themes. Finally, the analysis was shaped and finalized into a reportable form. (Clarke & Braun 2006.)

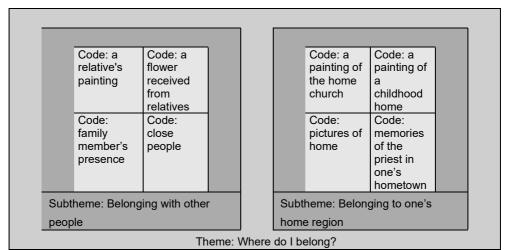


Table 7. Example of codes as building blocks of themes.

4.4 Ethical considerations

Research ethics were carefully considered in each step of the study (Wiles 2013, pp. 1-8). The study was conducted following the Finnish national legislation, principles of the WMA Declaration of Helsinki (World Medical Association 2013) and the principles of biomedical ethics which include respect for autonomy, nonmaleficence but beneficence and justice (Beauchamp & Childress 2019). The research was conducted according to the Finnish Code of Conduct for Research Integrity (Finnish National Board on Research Integrity 2023).

For the first (Paper I) and second (Paper II) sub-studies, the statement of the ethics committee was not required, because no vulnerable groups were involved. For the third (Paper III) and fourth (Paper IV) sub-studies, an affirmative statement was received from the Ethical Committee of the University of Turku (Statement 37/2017). The ethical review was required because older people with dementia were participating, and their possible vulnerability must be considered (Diaz-Gil et al. 2023). The study was approved also by the relevant authorities of the organisations within it was conducted by signing written research permits. In addition, the substudies met the ethical requirements of the scientific publications.

Philosophically, spirituality as a concept can be seen as linked to ethics (Carr et al. 2011). The justification for the study, as an important part of research ethics, was introduced in the beginning of this summary. The gap of knowledge solely was not the justification to conduct a study but there was evidence and general agreement on that older people could benefit from this research. According to previous studies, supporting spirituality may be beneficial for older people with dementia (Palmer et

al. 2022). Spiritual support may help older people living with dementia to maintain the meaning and purpose in life and to promote their dignity (Chen et al. 2019).

The assessment of risks and benefits of the study for the participants and for older people with dementia in general, was challenging. However, supporting spirituality is a building block for culturally sustainable nursing care of older people with dementia. It was considered important that older people with dementia themselves were included in research that concerns their experiences and may contribute to the development of their nursing care (Hougham 2005; O'Connor et al. 2022; Diaz-Gil et al. 2023).

The participants were guaranteed anonymity in all the phases of the study. The authentic quotations and other reporting were conducted so that individuals will not be recognised. To protect privacy and anonymity, the participants were instructed that no identifiable people could be seen in the photographs (Oakes et al. 2022). The same instructions were given to the professional photographer who technically conducted the photography. The participants were also assured that they can withdraw from the study without any explanations. They were carefully observed for the signs of fatigue or distress in interviews. This was done in accordance with the principle of harm minimization (Traianou 2020, pp. 86-110). However, no one withdrew from the study.

Interview recordings and transcribed manuscripts as well as photographs were stored digitally password-locked so that only the researcher had access to the raw data. The participants' demographic data was stored separately and instead of names, codes were used to ensure their anonymity. In publishing the results, pseudonyms were used when needed. This was done in the reporting of the third sub-study (Paper III), when the humanity of the participants was emphasised by naming them, but their anonymity was protected by using pseudonyms.

Participants in the third and fourth sub-studies also included older people living with dementia. They can be considered a vulnerable group when participating in the study (O'Connor et al. 2022). However, the concept of vulnerability has been considered in research and it is not always justified to make a presumption of vulnerability by belonging to a certain group (Racine & Bracken-Roche 2019). Ricoeur has considered the relationship between autonomy and vulnerability. According to him, the basic assumption is human autonomy, which, however, is the subject of constant evaluation when faced with fragility and vulnerability (Hettema 2014). Anyway, in this study, the researched phenomenon was sensitive (Berry 2015) and older people with dementia were involved. Therefore, special attention was paid to the voluntariness of participation and the participants' understanding of what they were involved in. This was assured during the interviews.

All the participants were given both oral and written detailed information about the study prior to the interviews. Informed consent forms were signed by all the participants. There has been much debate about the ability of people with dementia to give informed consent (Hellström et al. 2007; O'Reilly et al 2019; O'Connor et al. 2022). Vulnerability has been linked to the lack of capacity to provide free and informed consent (Racine & Bracken-Roche 2019). Therefore, consents of older people with dementia were confirmed by their family members. This choice did not deny older people with dementia their voice but ensured it (O'Reilly et al. 2019). It has been noted that during the research, older people with dementia may benefit from the presence of their family members (O'Connor et al. 2022).

An evaluation of the ability to informed consent based solely on cognitive tests or clinical assessment could deny decision-making to people with dementia who would be able to decide. (O'Reilly et al. 2019.) The steps taken to assess the ability of older people with dementia to consent are described in paper IV.

5 Results

In this chapter, the results of the narrative literature review (Paper I) and the three qualitative sub-studies (Papers II-IV) will be presented. Finally, the results of the sub-studies will be summarized. The more detailed results can be found in the original papers (I–IV).

5.1 Supporting the spirituality of older people with dementia

5.1.1 Supporting the spirituality of older people with dementia in literature

In the literature review (Paper I), an overall understanding of how and in what kind of environments the phenomenon had been studied, was achieved. Gaps on existing literature were identified.

The findings of the narrative literature review (Paper I) based on inductive qualitative analysis of selected articles (n=10), revealed the precursors and barriers for spiritual support in nursing care of older people living with dementia. Elements of spiritual support were identified. (Figure 7.)

Prerequisites for supporting the spirituality of	Respect for older people with dementia despite decreased cognition		
	Accepting older people with dementia as they are		
older people living with	Love		
dementia	Compassion		
Elements of supporting the spirituality of older people with dementia	Supporting religious activity		
	Enabling connections		
	Reflection of nurses' own spirituality		
	Nonverbal communication		
Barriers to	Lack of nursing professionals' time		
supporting the	Nursing professionals' low competence in supporting spirituality		
spirituality of older people with dementia	Nursing professionals' doubts about the ability of older people with dementia to consider spirituality		
	Low organizational support		
	Older people with dementia might be dependent on other people in spiritual support		
	Older people with dementia might have difficulties in expressing their spiritual needs		

Figure 7. Prerequisites for, elements of and barriers to supporting the spirituality of older people with dementia in nursing care.

Based on the findings, some interventions utilised by nursing professionals were identified as means to support the spiritual needs of older people with dementia. Supporting spirituality was identified to be multi-professional, cooperative, and reciprocal occurring in everyday nursing. (Paper I.)

5.1.2 Supporting the spirituality of older people with dementia from the perspective of nursing professionals

In the second sub-study, the aim was to describe the nursing professionals' lived experiences of supporting the spirituality of older people with dementia (Paper II).

Participants defined spirituality as a continuum between the secular and the religious, but also as a force inherent in humanity. They were learning about and developing an understanding of the spiritual needs of older people with dementia through verbal and nonverbal expression and through the information of spiritual background. With the gained knowledge about spiritual needs, nursing professionals were meeting the needs by approaching the older person as a valuable person and by paying attention to and supporting his/her personal philosophy of life. (Figure 8.)

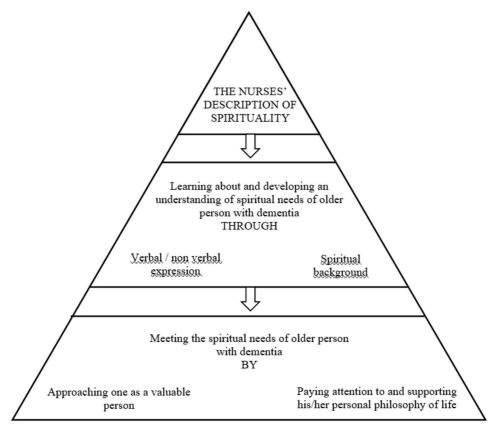


Figure 8. Illustration of nursing professionals' experiences of supporting the spirituality of older people living with dementia.

5.1.3 Supporting the spirituality from the perspective of older people with dementia and their family members

The findings presented here result from a hermeneutic interpretation according to Ricoeur's theory. This means the circle of naïve reading, structural analysis, and comprehensive understanding (Paper III). Ricoeur's theory of interpretation as a method of analysis is strongly linked to the results (Missel & Birkelund 2020), so the results are presented through the stages of interpretation.

Naïve reading

In naïve reading, the transcribed manuscripts were read through, and without analysing or interpreting, the thoughts of what was the text about, "what the text says (Simms 2003, p. 132)", were written down. This revealed the basic idea of the text that was formulated in the original paper III:

"The personal meaning given to spirituality, created a background which could be used to support the spirituality of older people living with dementia. This support consisted of addressing and meeting spiritual needs individually using different elements of spirituality. The results showed that participants living with dementia needed spiritual support to maintain meaning and purpose in their lives. The participants also outlined some challenges to the spiritual support in their nursing care (Toivonen et al. 2023, pp. 5)."

Structural analysis

The naïve reading was guiding to find the themes in structural analysis and the comprehensive understanding confirmed them (see Geanellos 2000). Through structural analysis, five themes were found to describe the meanings immersed in the text:

- 1. Personal understanding of spirituality as a basis for supporting spirituality
- 2. Addressing the individual spiritual needs of older people living with dementia
- 3. Meeting the spiritual needs of older people with dementia through the elements of spirituality
- 4. Meaning in life through spiritual support
- 5. Challenges in supporting spirituality in nursing care.

Comprehensive understanding

In the comprehensive understanding, researcher's preunderstanding, naïve reading, structural analysis, and relevant literature were all combined and the entity of the phenomenon was opened (Charalambous & Kaite 2013). This approach allowed for a multifaceted interpretation of the phenomenon.

The personal meaning that older people with dementia, their family members and nursing professionals gave to spirituality, formulated a basis for supporting spirituality. This basis was a guide in addressing spiritual needs of older people with dementia. Spiritual needs were individual. From the perspective of older people living with dementia, and their family members, supporting spirituality in nursing was experienced through religion, meaningful relationships, nature, and arts. When an older person with dementia experienced spiritual support, that support helped person to enhance the sense of meaning in life. (Figure 9.) However, the participants felt that there were some barriers to the realization of spiritual support in nursing practice.

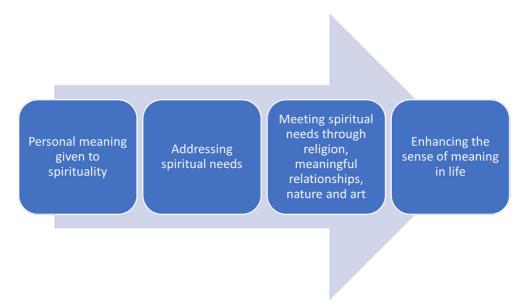


Figure 9. Supporting the spirituality from the perspective of older people with dementia and their family members.

Despite the homogeneity of the participant group, the concept of spirituality was defined in varying ways. The definitions covered a secular approach to the concept as well as a definition tied to religion. The majority placed the concept somewhere between these two extremes and understood it broadly. Spirituality was understood to express the elements in human life through which individuals seek experiences of purpose and meaning in their lives. These elements could be physical or reach beyond the boundaries of physical world and to be supernatural in nature. The experience of meaning in life included individual symbolism, which connected the experience to the individual's inner spirituality.

The spiritual needs of older people with dementia were not perceived to decrease because of the disease, although it could become more difficult to recognize them. Older people with dementia needed comfort and support to cope with a serious illness, and spirituality was perceived to be an important part of this support.

Meeting spiritual needs was possible through meaningful relationships, religion, nature, and art. The individual life experiences and views of each person with dementia affected which of these elements were perceived as spiritual. The importance of meaningful relationships was emphasized. Closed ones supported the person with dementia by remembering, while the person with dementia was fumbling with the memories. For some participants, religion was an important resource supporting spirituality. Through religion, spirituality could be supported,

for example, through prayers and religious music or literature. For some, physical objects related to religion, like Bible or icons, were important.

Many participants emphasized the importance of nature as a source of meaning and purpose in life. In nature, one could have a sense of connection with the surrounding world. If physical nature experiences were no longer possible, the participants believed that virtual nature experiences could be useful for older people with dementia. For some participants, art was a source of spiritual experience. In this case, art was not only physically sensed, but profoundly experienced. For example, poetry, visual arts, and music could support spirituality.

In the participants' experiences, spirituality was related to the meaning and purpose in life. For example, art could be just art for someone, but for another it symbolized spirituality through the experience of the meaning in life. In spirituality, one deepened the experience of the physical world to where a person's life has a meaning even if the ability to communicate verbally has been loosed or physical participating in the world around has become challenging.

The barrier for supporting spirituality in nursing care was the nursing professionals' schedule, where there was not necessarily time for unhurried presence. Spirituality was also not experienced to be an easy phenomenon for all nursing professionals to approach.

5.2 Caring and living environment supporting the spirituality of older people with dementia – ways of being-in-the-world

In analytic phase, the spirituality-supportive elements of caring and living environment of older people with dementia were analysed. In this analysis, the interview data was combined with visual data created by photographing the caring and living environments of older people with dementia. Through the interpretation of the data, three themes were derived and formulated as questions expressing older people's search for meaning and purpose in life (Figure 10).

The role of the caring and living environment in supporting spirituality was three folded:

- 1. Supporting the personality of an older person with dementia through the elements that support spirituality.
- 2. Informing those participating in the care about the individual spirituality of older person with dementia
- 3. Giving those participating in the care concrete means to support the spirituality of older person with dementia.

In the caring and living environment, nursing professionals, older people with dementia and their family members together searched for answers to existential questions and through them for spiritual purpose and meaning in their lives. This collaborative journey often involved deep conversations and shared experiences that fostered understanding. For instance, they might explore themes of identity, reflecting on memories. Through activities such as, music, and art, they found ways to express their emotions and connect on a deeper level. This process not only enriched their relationships but also provided comfort in navigating the complexities of life with dementia.

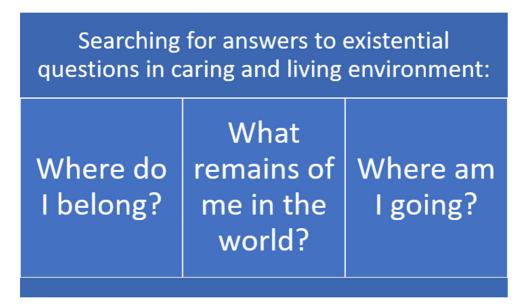


Figure 10. Spirituality supportive caring and living environment of older people with dementia.

Sense of belonging was seen as essential in spiritual support of older people with dementia. This included sense of belonging with other people, sense of belonging to one's home region and one's own home as well as to the world around. The participants also experienced that it is important to leave a mark of one's life in the world. The older people with dementia were faced with a severe disease that threatened their life. They felt that their life could continue in remaining people and memories. At the same time, they were also considering the end of their lives and possibly after life issues. Some were comforted by the thought of life after death in a religious sense. Some others that were not religious, were thinking about their loved ones who had died before them. The thought gave them the courage to face the end of life even though they were not sure about life after death or did not consider it possible.

The participants described spirituality in their caring and living environment in a variety of ways with photographs (Figure 11). These images captured moments of reflection, connection, and peace, illustrating how spirituality was woven into their daily lives. Some participants highlighted the importance of nature. Others focused on meaningful people, emphasizing the role of social connections in their spiritual experiences. Through these diverse representations, it became clear that spirituality was an integral part of their well-being and personality.







Figure 11. Examples of spirituality-supportive caring and living environment in photographs.

5.3 Summary of the main results

The overall aim of this study was to achieve a comprehensive understanding of supporting the spirituality of older people living with dementia in their caring and living environments. The phenomenon was approached through the lived experiences of older people with dementia and their family members as well as nursing professionals. The understanding of the phenomenon was further expanded by

analysing the environment together with the participants as a symbol of and support for spirituality. The results and outcomes of each sub-study are presented in table 8.

 Table 8.
 Results and outcomes of research steps.

PHASE	STEP	RESEARCH QUESTIONS	MAIN RESULTS	OUTCOMES
DESCRIPTIVE PHASE I	Step I	RQ1. How has spirituality been supported in the nursing care of older people with dementia in earlier literature?	Supporting spirituality is concerned with supporting religious activity, enabling connections, nurses' reflections on their own spirituality, and nonverbal communication. The benefits from the support of spirituality are reciprocal and occur in everyday nursing.	Description of earlier studies on phenomenon, synthesis of their findings. Identification of gaps in existing literature.
	Step II	RQ2: What are the experiences of nurses on supporting the spirituality of older people with dementia?	Supporting the spirituality of older people with dementia is understanding their spirituality within a framework of personcenteredness and individuality. The nursing professionals understand the spiritual needs of older people with dementia through both verbal and nonverbal expression and by learning about older people's individual spiritual backgrounds. Meeting spiritual needs means approaching the person with dementia as a valuable human as well as paying attention to and supporting personal philosophy of life within nursing care.	Understanding nursing professionals' lived experiences of the phenomenon.
	Step	What are the experiences of older people with dementia and their family members of spiritual support in nursing care?	Older people with dementia need spiritual support based on their personal understanding of spirituality. The four elements of this spirituality are religion, meaningful relationships, nature, and art. The barriers to spiritual support include the competence and abilities of nursing, time available, presence and experience.	The comprehensive understanding revealed a new contextual interpretation of being-in-the-world of the phenomenon from the perspective of older people with dementia and their family members.

PHASE	STEP	RESEARCH QUESTIONS	MAIN RESULTS	OUTCOMES
ANALYTIC PHASE II	Step IV	What kind of caring and living environment supports the spirituality of older people living with dementia experienced by themselves and their family members?	Spirituality is a continuum within human life, manifested through and in the environment even if older people with dementia are not able to express themselves. The participants' experiences of spirituality within the caring and living environment were summarized into three existential questions: "Where do I belong?", "What remains of me in the world?" and "Where am I going?" Caring and living environment that supports spirituality gives opportunities to search answers to these questions. The environment guides towards experiences of the meaning and purpose of life.	An analysis of spirituality supportive caring and living environment of older people with dementia.

A descriptive theory of supporting the spirituality of older people living with dementia in their caring and living environments was derived from the findings of this study (Figure 11). This was conducted by analytically synthesizing knowledge of four sub-studies. In the theory, the findings of all four sub-studies were combined. The theory is contextual and based on lived experiences of older people with dementia, their family members and nursing professionals as well as earlier literature of the phenomenon.

Reynolds' research-to-theory -strategy as introduced by Lynham in a book edited by Swanson & Chermack (2013, p. 34) was adapted in developing the theory. First, the phenomenon "Supporting the spirituality of older people with dementia in their caring and living environment" was selected. The characters of the phenomenon were listed in the literature review (Paper I, Figure 6). This included specifying prerequisites for, elements of, and barriers to spiritual support. Secondly, the phenomenon was studied from different perspectives (Papers II-IV). The results of these three sub-studies were added into the results of the literature review. Thirdly, the data of qualitative studies were analysed. Fourth, the analysed data was formalized into a figure (Figure 12) to understand the phenomenon comprehensively. Through this process, the pieces of information collected in the sub-studies were

combined and the phenomenon was assembled into a theoretically articulated whole (Charalambous et al. 2009).

Supporting the spirituality of older people with dementia in their caring and		
living environments		
Searching for answers to existential questions:		
	• Where do I belong?	
	• What remains of me in the world?	
	• Where am I going?	
Prerequisites	Respect	
for supporting	Accepting older individuals with dementia as they are	
the spirituality	Love	
of older people	Compassion	
with dementia	Personal meaning given to spirituality by	
	Nursing professionals	
Tinl4	Older people with dementia and their family members	
Learning about and developing	Through verbal and nonverbal communication	
and developing an	Through verbal and nonverbal communication Through spiritual background	
understanding	- Through spiritual ouckground	
of the spiritual		
needs of older		
people with		
dementia		
3.6		
Meeting the	By paying attention to and supporting personal philosophy Stiff in the division and supporting personal philosophy	
spiritual needs	of life including religious activity Through meaningful relationships	
of older person with dementia	Through meaningful relationships Through nature	
with dementia	Through nature Through art	
Dania na 4a		
Barriers to	Due to organization • Insufficient time resources	
supporting the	Deficiencies in organizational support	
spirituality of older people	Due to nursing professionals	
with dementia		
with deficitia	Deficiencies in the competence of nursing professionals	
	Due to older people with dementia	
	Dependence on other people in spiritual support	
D (1) 0	Difficulties in expressing spiritual needs	
Benefit of	Enhancing the sense of meaning in life	
spiritual		
support		

Figure 12. The components of the descriptive theory on supporting the spirituality of older people with dementia in their caring and living environments.

The context of the theory are the caring and living environments of older people with dementia, where they themselves and their spiritual needs are central. Humans are seen as part of their environment living in a constant interaction with their physical, social, and symbolic environment. An environment that supports spirituality reminds older people with dementia of who they are and what are the elements from which their spirituality formulates and how it manifests. Each older person with dementia has an own spiritual background, which serves as a ground for their personal views of spirituality. These views are influenced by lived experiences and may be rooted in childhood, youth, adulthood, or older age. Spirituality, as a part of the continuum of life, changes through life. With dementia, a particular lived phase of one's spiritual life can be emphasized. Therefore, the nursing professionals are required sensitivity and willingness to listen to verbal and non-verbal expression about spiritual needs.

Family members might have valuable information about the spiritual background of an older person with dementia. The views of family members are filtered through their own lived experiences and, as such, they are interpretive. Furthermore, when supporting spirituality, interpretability is always present. If older people with dementia are no longer capable of expressing themselves, this is the case with their other needs as well.

However, spirituality is an individual and subjective phenomenon. In addition to the person with dementia, also nursing professionals each have their own views and lived experiences of spirituality. It is important for nursing professionals to recognize and reflect on their own spiritual background. This reflection helps them to separate their own experiences from the experiences of older people with dementia and enter the *life-world* of the person with dementia in spiritual support. The experience of spirituality is heterogeneous even within a homogeneous group, and it is not possible to draw definitive conclusions based on, for example, a person's religion.

Supporting spirituality in nursing care is not about performing tasks. Respect, acceptance of older people with dementia as they are, love and compassion are prerequisites for spiritual support. They are an integral part of spirituality as well. Based on these, nursing professional faces an older person with dementia as a valuable person. Without this appreciative starting point, it is not possible to enter the sensitive innermost part of humanity, where spirituality springs from.

Nursing professionals get information about the spiritual needs of older people with dementia through verbal and non-verbal communication. In early stages of dementia, it may still be possible to express needs verbally. By progression of the disease, the role of family members as advocates is increasing. In that case, the support of spirituality remains based on a second-hand account. However, nursing professionals can observe older person's reactions, expressions, and gestures to understand and meet their spiritual needs.

The spiritual support provided by nursing professionals can also be non-verbal or verbal. Nonverbal support includes being present, staying by one's side. Verbal and non-verbal support for spirituality consist of supporting the person's individual religious or non-religious philosophy of life, as well as supporting meaningful relationships. In addition to this, spirituality can be supported through nature and art. The forms of support emphasize what brings purpose and meaning to an older person's life. For someone, the profound meaning in life can be found in religion, but for another, in meaningful relationships, nature, art or in various combinations of these elements.

The barriers to supporting spirituality in caring and living environment of older people with dementia are related either to nursing professionals and care organizations or older people with dementia themselves. The barriers related to nursing professionals and care organizations include nursing professionals' lack of time and low competence in conducting spiritual support. Some nursing professionals have doubts about older people with dementia to benefit from spiritual support. These doubts occur when considering advanced dementia. Care organizations do not always support nursing professionals in conducting spiritual care. What makes spiritual support especially challenging when people with dementia are involved, is their growing dependence on other people in meeting their spiritual needs. As the disease progresses, also difficulties in expressing spiritual needs increase.

Supporting spirituality in caring and living environment focuses on the experiences of an older person with dementia, but the benefits can be reciprocal. While an older person with dementia is looking for the meaning in life supported by nursing professional, the meaning in the nursing professional's work is also emphasized. An older person with dementia is looking for answers to existential questions: "Where do I belong?", "What remains of me?" and "Where am I going?" Nursing professionals and other people involved in care can be supportive in this search, building together a caring and living environment that supports spirituality.

6 Discussion

6.1 Reflection of the methods

From a hermeneutic-phenomenological philosophical starting point, the phenomenon was approached through a literature review and three qualitative studies. The aim of this study was to achieve a holistic understanding of supporting the spirituality of older people living with dementia in their caring and living environments. This understanding was strived for by listening to the people whose experiences was seen essential to understand. The research questions were aiming to increase understanding, so answers were sought through a qualitative approach (see Beyea & Nicoll 1997).

In this study, the narrative literature review was first conducted to find out how the phenomenon had been researched before. A gap in the literature was found. There was not enough understanding of how nursing professionals, older people with dementia themselves and their family members experienced spiritual support in caring and living environments. That is why it was decided to interview them and ask them about their lived experiences.

Nursing professionals were interviewed individually. Spirituality is a very sensitive area to discuss including person's worldview and possibly religious conviction. People might not want to share their views on spirituality with many. (Morgan et al. 2013; So et al. 2023.) That was the reason for individual interviews even though time resources were needed for the preparations and the interviews, and the number of participants remained small. It would have been possible to interview more nursing professionals in groups, but the results could have remained more superficial. In individual interviews nursing professionals opened themselves to indepth discussions about the phenomenon and their own lived experiences.

Older people with dementia were interviewed in dyads with their family members. The reasons for conducting the interviews of older people with dementia and their family members in dyads were as following:

1. The lived experiences of both older people with dementia and their family members were of the interest in this study.

- 2. It has been found more comfortable for people with dementia to participate together with their family members (Hellström et al. 2007; Pratt 2001).
- 3. Dyadic interviews were considered to stimulate discussion about experiences that might not have been either recognized or remembered in individual interviews (Clarke & Keady 2002; Morgan et al. 2013).
- 4. Dyadic interviews offered a better opportunity for older people with severe dementia to participate in the study (see Head et al. 2021).
- 5. The family members could confirm the consents of older people with dementia and help researcher in observing their possible fatigue or discomfort during the interviews (see Hellström et al. 2007).

The dyadic interviews were conducted in the homes of older people with dementia. This was essential because the aim was to also understand the environment that supports spirituality. Entering the own world of older people with dementia, their caring and living environment, was considered necessary to achieve this aim. The spirituality-supportive caring and living environment was seen essential to approach both verbally and visually through photography. On one hand, participating in research was seen to be easier because the older people with dementia did not need to leave their own home for interviews (see Clarke & Keady 2002, p.34). On the other hand, older people with dementia and their family members could be nervous about the researcher and the photographer visiting their home environment. Some of the participants did express their concerns regarding, for example, the cleanliness of their home, but they were assured that it was not relevant to the implementation of the study.

Hermeneutic phenomenology was seen as a suitable way to understand the lived experiences of the participants. In hermeneutic phenomenology, understanding a person is not being separate from other person in making assessment but being bound to another person and on the same line with him (Gadamer 1975; Bengt Kristensson 2022). We cannot completely enter another person's experiences (see Smythe & Spence 2022, p. 33) of spirituality. Nonetheless, it is fascinating to approach the experiences of other people. Because we humans have infinite opportunities to understand spirituality, and because the same idea can be interpreted in many ways (McSherry & Cash 2004), the journey of exploring the boundless variety of these experiences is a challenging task. This approach to phenomena as unattainable and at the same time approachable is attuning to hermeneutic phenomenology (Smythe & Spence 2022, pp. 21-36).

In the second sub-study, Heideggerian hermeneutic phenomenology was applied (Tuohy et al. 2013). This interpretive philosophical background combined with inductive content analysis (Graneheim & Lundman 2004) produced a comprehensive understanding of the nursing professionals' lived experiences. In 1996, Cooper (1996) wrote about Heidegger that the philosopher has had an

influence upon variety of disciplines "and even, so I'm told, nursing studies (Cooper 1996, p.1)". From that on, his influence upon nursing studies has become evident (e.g., Darbyshire & Oerther 2021).

In the third sub-study, Ricoeur's philosophical approach was applied in planning and conducting the study as well as in interpreting the data (see Singsuriya 2015). Ricoeur (1981, pp. 202) has noted: "... the spirituality of discourse manifests itself through writing, which frees us from the visibility and limitation of situations by opening up a world for us, that is, new dimensions of our being-in-the-world." In the light of researcher's own pre-understanding of the phenomenon, the 'writing' that is, the narratives of the participants (papers II-IV), were interpreted. The interpretation revealed a new world where older people with dementia were living and experiencing spiritual support in their caring and living environment. The spirituality of the discourse manifested itself in this appropriating a 'new dimension of our being-in-the-world'. (Ricoeur 1981, pp. 202.) Hardwick (2017) explains the focus of Ricoeur's theory of interpretation as "the glimpses of universal aspects of the everyday". Spirituality is in those glimpses that the interpretation revealed.

In the fourth sub-study, the photo-elicitation method (e.g. Harper 2002) was adapted in hermeneutic-phenomenological research. Visual expression was utilized to help participants analyse spirituality supportive elements in the caring and living environment of older people with dementia. From hermeneutic phenomenological perspective, older people with dementia were seen as constantly interacting with their caring and living environment creating meanings and interpretations of the phenomena (see Charalambous 2014). This view was supported by Kim's (2010) theory of the nursing environment, which also emphasizes a person's constant interaction with the physical, social, and symbolic environment (Kim 2010, pp.219-221).

Currently, with the spread of social media, photography is used for self-expression much more than before (Holm 2020). However, not all older people have necessarily adopted this if social media has remained alien to them (PEW Research Center 2019). Anyway, in everyday life, many photographs or other visual images are seen and interpreted daily (Holm 2020).

There was a lot of discussion about how to use the photo-elicitation method with the participants with dementia. The decision to use a professional photographer was an appropriate choice for several reasons. First, the ability of older people with dementia to learn how to use a camera and take pictures themselves may be impaired (Renn et al. 2021). Therefore, the technical side of photographing would require both time and attention. Second, if the researcher had taken pictures during the interviews, the concentration on the conversation might have weakened during the photographing. Thirdly, using a professional for photography affected the quality of the photographs and, with that, their usability in analysis and reporting. The use of a professional in photography in nursing research is rare. Usually, either the researcher

or the research participants take the pictures, or ready-made pictures are used in the research (Holm 2020).

However, the prospects of the photographer's own interpretation in his productions required consideration. Here we return to the root question of hermeneutics. Every phenomenon is inevitably subject to interpretation (Ray & Locsin 2023). Each individual brings an own interpretation to the phenomenon (Ray & Locsin 2023). Therefore, the photos would possibly have been different if someone else interpreted the participants' descriptions of an environment that supports spirituality. However, the participants themselves indicated the objects to be photographed.

An interesting idea of using photography in researching people with dementia is the connection of photographs with memories (Berger 1992). Photos evoke memories and things are photographed to remember them (Harper 2002). As dementia advances, the memories recorded in the photos become more prominent. This was manifested in that many participants wanted to take photos of photos of people important to them. Photographing sparked a lot of discussion and emotions and memories of spirituality.

However, after utilizing photo-elicitation in understanding the spirituality-supportive elements in the caring and living environment of older people with dementia and their family members, Harper (2002) and Prosser (2007) are agreed in that the method is useful for understanding symbolic meanings in built environment. Furthermore, the use of visual method gave older people with dementia another way in addition to verbal communication to express their experiences about an abstract phenomenon (Morgan et al. 2013).

Building a descriptive theory based on hermeneutic-phenomenological research turned out to be possible and rewarding. The same conclusion has also been reached by Charalambous et al. (2009).

After conducting this study, my preunderstanding about the phenomenon has changed and continues changing as I continue research in this endless hermeneutic circle. Like Noel Harrison (1968) sings: "Like a circle in a spiral, like a wheel within a wheel, never ending or beginning on an ever-spinning reel. As the images unwind, like the circles that you find in the windmills of your mind."

6.2 Reflection of the results

In this study, understanding of supporting the spirituality of older people living with dementia was researched. In this chapter, the findings of the study are reflected. Belonging to the nature of the hermeneutic circle, the findings are not final or closed, but the circle could be continuously rotated in ever-changing environments (Charalambous et al. 2008).

The contribution of this study to gerontological nursing practice is significant (see Bambusch et al. 2023). This study produced new way of understanding the life-

world of older people with dementia in three levels: 1) The supporting perspective to the spirituality of older people with dementia is novel and yet central from the caring point of view, 2) the role of the environment in supporting spirituality can be understood through the results of this study and 3) descriptive theory on supporting the spirituality of older people with dementia derived from the findings of this study offers novel understanding about the phenomenon. The theory organizes knowledge for use in nursing professionals' education, as support for nursing practice, in research and in society. This comprehensive understanding opens the life world of supporting the spirituality of older people with dementia in a new way combining earlier literature with the perspectives of nursing professionals, older people with dementia and their family members.

The findings of the sub-studies are consistent with previous research results, adding to them the aspect of supporting the spirituality of older people with dementia in their caring and living environment. The understanding of the environment in supporting spirituality brings a new perspective to the phenomenon. In the earlier research, supporting the spirituality of older people with dementia and the caring and living environment that supports their spirituality have not been studied this extensively. The results of the study combine the views of older people with dementia, their family members and nursing professionals on how the spirituality of this group of individuals can be supported in nursing care. In addition to that, the research results have brought out concrete nursing interventions for supporting spirituality. The philosophy behind the individual support of the spirituality of people with dementia has also been opened in a new way. According to the results of this research, a person's inner spirituality does not end at the decreasing of verbal expression but is at the core of humanity and includes individual experiences of the purpose and meaning in life, which can be supported even when the dementia progresses. Caring and living environment play a key role in this support.

The Christian roots of Western nursing have become detached, and the base of today's nursing is secular (Widerquist & Davidhizar 1994). With the detachment of Christian roots, many early nursing theorists were influenced by Eastern mysticism (Sarter 1988). Today, in professional nursing, holistic nursing and specialization are balancing (Frisch & Rabinowitch 2019). Spirituality in nursing can be seen as both its own area of expertise and as a part of holistic nursing (Murgia et al. 2020).

In the way the participants defined spirituality, the pluralization of culture and an expansion of the concept of spirituality (see Murgia et al. 2020) could be noticed. Although some participants considered spirituality consistent with religion, for most participants the meaning of the concept was much broader. This has not been the case always in earlier research (Katsuno 2003, Beuscher & Grando 2009) when participants have defined spirituality only by religion. Too broad definition has been criticized (Reinert & Koenig 2013). Reinert and Koenig (2013) see it problematic if

spirituality is defined through the meaning in life (e.g., Tanyi 2002). They argue that also people without sense of meaning in life, like people with severe depression, can be spiritual. If spirituality is defined through meaning in life, measures of spirituality that are derived from that definition, would estimate those people as not spiritual. (Reinert & Koenig 2013.) The definitions of the concept of spirituality are central also in the context of older people with dementia. They may not be able to rise "above their circumstances and find peace (Britt & Hamilton 2023)", but their spirituality does not disappear.

Considering the results of this study, spirituality does not refer to the peace of mind or the purpose and meaning in life itself, but to the way older people strive toward them. Older people living with dementia can be very anxious and restless and yet seek peace and meaning in life in their own way. There is difference between defining spirituality through **having** a sense of meaning in life than defining it through **searching** for meaning in life.

However, in this study, as well as in some other studies (e.g., Daly et al. 2019; Haufe et al. 2024) spirituality was understood broadly as an aspect of humanity. When understood this way, spirituality can be considered to affiliate with all people. However, a person's own experience of whether the concept of spirituality affiliates with him/her or not, needs to be respected. People with dementia themselves decide whether spirituality is part of their life and whether they want spiritual support or not.

The participants of this study were talking about different ways assessing the spiritual needs of older people in nursing care. However, they did not bring up any tools that could be used to assess these needs. Furthermore, nursing professionals did not mention of having used or heard of any measurement tools to assess the spiritual needs of older people with dementia. The lack of special tools to assess their spiritual needs has been noted also by Britt et al. (2023). However, nursing professionals were seeking for an understanding of spiritual needs in many ways. In addition to verbal expression, they utilized spiritual history of older people with dementia as well as hints given by their physical environment. They were also interpreting non-verbal communication, such as gestures and facial expressions.

Religious and spiritual backgrounds in spiritual support of older people with dementia were highlighted later by Britt et al. (2023) as well. In their literature review, Britt et al. (2023) highlighted older people with dementia expressing their spiritual needs by verbal and non-verbal communication. They were including the second and the third sub-studies of this dissertation in their integrative review (Britt et al. 2023).

In this study, the older people living with dementia and their family members experienced spiritual support in nursing through religion, meaningful relationships, nature, and arts. This is consistent with earlier literature on spirituality. Spirituality has been defined as an ultimate meaning mediated through religion, relationship,

creation/environment, and the arts. (MacKinlay & Trevitt 2015.) Meaningful relationships with other people have been highlighted in the literature on spirituality of older people with dementia (Daly et al. 2019; Britt & Hamilton 2023) and in this study, they were of great importance. Furthermore, spirituality has been defined through connectedness (Britt & Hamilton 2023). In this study, older people with dementia expressed how important it was for them to continue their "artistic and poetic creativity (Jewell 2003, pp. 15-16)". This included art both as experienced and as one's own creativity. For example, one of the participants wanted to recite a poem by a famous poet from memory, and another wanted to read a poem she had written herself. This is how they expressed their inner human through art; that core of humanity that they experienced as spirituality. In this emphasis on art and poetry, the participants placed older people with dementia at the heart of hermeneutic phenomenology, where the basis of human existence is "poetic" (Heidegger 2014, pp. 59-65).

The results of this study strengthened the understanding of spirituality as a multidimensional phenomenon. However, these four areas (religion, meaningful relationships, nature, and arts) did not completely cover the support of spirituality in the nursing care of older people with dementia. As previously mentioned, understanding of spiritual needs is required, as well as respect, acceptance, love, and compassion. When dementia progresses, these attributes of caring attitude, are highlighted. When there are no more words, the connection is found behind them in the core of our common humanity. In this mystery of humanity, spirituality is profound.

Therefore, supporting spirituality is holistic care. It is not a question of tasks, but of the approach and attitude to nursing care. Anyway, some nursing interventions to support the spirituality of older people with dementia were introduced in paper I. They included supporting religious activities, enabling connectedness, reflection of nurses' own spirituality, nonverbal communication as well as small things and attitudes in everyday nursing (Paper I). Providing religious activities and facilitating religious rituals have been highlighted also in other studies (Ødbehr et al. 2017; Britt et al. 2023). Based on the results of this study, religion should not be overemphasized when talking about spirituality and supporting spirituality. Spirituality included worldviews outside of religiosity. Religion was a central part of spirituality only for some older people with dementia. However, they need external support with their spirituality, especially when the disease progresses. This has been noted in other studies as well (e.g., Britt et al. 2023).

Consistent with this study, it has been noted also in other literature that individuality plays a strong role in the experiences of spirituality (Britt & Hamilton 2023). In this study, it was highlighted that nursing professionals should not make the mistake of supporting the spirituality of older people with dementia from their own experiences. The starting point for support should always be the older person's own experience of spirituality. This requires nursing professionals to be aware of

and reflect on their own spirituality. Sensitivity is needed to separate their own experience from the *life-world* of another person. Nursing professionals can support the spirituality of older people with dementia when they have knowledge and understanding of the different manifestations of spirituality.

The environment that supports spirituality was summed up in the *life-world* of the participants with existential questions, where the meaning and purpose of life was sought. These questions were: "Where do I belong?", "What remains of me in the world?" and "Where am I going?". The individual symbolic meanings older people with dementia gave to their physical and social caring and living environment, could support their spiritual being.

The participants of this study highlighted the sense of belonging (Where do I belong?) in spirituality-supportive environment. This included belonging together with other people as well as belonging to one's home region, own home and to the world around. This sense of the familiar and of belonging made older people with dementia feel safe within their environments. Although the sense of belonging has not previously been connected to an environment that supports spirituality, it has nevertheless been found that it can be supported by the arrangement of common spaces in nursing homes (Johansson et al. 2022). In their study, Rykkje et al. (2023) concluded that spiritual well-being is connected to the feeling of home in nursing home residents.

The existential longing of older people with dementia to leave a mark on the world (What remains of me in the world?) and the reflection on the end of life's journey (Where am I going?) both reflect renunciation; relinquishment of memories as the disease progresses and eventually the "possibility even of the loss of being", as Heidegger (2014, p.55) expresses it.

Congruent to other studies (Beuscher & Grando 2009; Daly et al. 2019), spirituality was seen as a lifelong journey. In the light of the findings from this study, supporting spirituality did not mean that an older person with dementia was a subject to some actions taken by a nursing professional. It was more like a journey made together, where both had their own previous experiences and views on spirituality in suitcases with them. This luggage determined how far they could travel together. Older people reached out to nursing professionals by expressing their spiritual needs verbally or nonverbally. When their needs were understood, the needs could be met. However, in this study, the participants felt that the spiritual needs of older people with dementia were not always met. This was seen to result of nursing professional's lack of competence and time. Viftrup et al. (2023) have noted the same barriers in spiritual care.

The findings of this study revealed that older people with dementia can benefit from spiritual support in a variety of ways. These benefits were seen to be reciprocal so that also nursing professionals could benefit from supporting the spirituality of older people with dementia in their work. Spirituality was seen to increase the quality of life of older people with dementia as well as the quality of their care. Spirituality

was considered to make older people with dementia happier and to give them joy and hope for the future as well as to reduce fear. Spiritual support helping to find hope has been highlighted in earlier literature as well (Daly et al. 2019). Spirituality helped older people with dementia in preparing for death and still feeling safe. It provided inner peace and confidence. Supporting spirituality was experienced to help coping with dementia as a severe condition. The role of spiritual support in coping has been noted in other studies as well (Daly et al. 2019; Britt et al. 2023). In this study, spiritual support was also seen to help older people with dementia to maintain meaning and faith in life. Supporting spirituality is included in holistic care (e.g. Scott Barrs 2020). It is not a nursing task but, as a nursing professional, encountering another individual on the basis of common humanity.

6.3 Limitations and rigor of the study

The group of participants in this study was quite homogenous as all the nursing professionals, older people living with dementia and their family members were living in the same area in Finland. All the nursing professionals and most of the older people and their family members were female. A larger number of male participants and the participation of individuals with other gender identities could have broadened the perspective on the phenomenon under investigation. However, recruitment was challenging.

Recruiting older people with dementia and their family members as dyads showed up to be challenging. Spirituality might be a difficult topic for some to discuss. The subject of the study may have contributed to the fact that only people with a particular interest in spirituality wanted to participate in the study. The same problem applies to other phenomena as well when the participation is based on the willingness to participate. In the case of spirituality, this could result, for example, that a large proportion of participants would be particularly religious. However, participants in this study also represented non-religious and even atheistic views. Several different Christian churches were represented.

The challenge was also the general understanding that dementia weakens the experience and expression of spirituality (Beuscher & Beck 2008; Daly et al. 2019). Dementia does affect abstract thinking as it progresses (Dalby et al. 2012; Haufe et al. 2024), but it has been found that people with dementia can discuss spirituality (Trevitt & MacKinlay 2004; Beuscher & Grando 2009; Jolley et al. 2010; Carr et al. 2011). This understanding was confirmed in this interview study. According to previous studies (e.g. Agli et al. 2015; Daly et al. 2019; Haufe et al. 2024), the experience of spirituality can even intensify as the dementia progresses (Carr et al. 2011), because spirituality is not a cognitive but an emotional matter in a person's

life (Haufe et al. 2024). Dementia often affects this kind of emotional element the least (Beuscher & Grando 2009; Carr et al. 2011).

The goal of this study was not to generalize but rather to provide a rich, contextualized understanding of supporting the spirituality of older people with dementia in their caring and living environments. However, by describing the research participants and the research process extensively, the aim was to ensure that the readers can define the generalizability of the research results based on this 'thick description'. The results of the study should be seen in the cultural context in which it was conducted. Purposive sampling and a relatively small sample create constraints on the widespread generalization of the results. However, in similar contexts, the results of the study can be utilized. (see Armour et al. 2009.)

When it comes to qualitative studies and especially with hermeneutic phenomenological approach, credibility is always an arguable issue (Charalambous & Kaite 2013). In hermeneutic phenomenology, the researcher is not seen as completely objective analysing the text as an outsider. This is not considered a problem in hermeneutics. The researchers bring their own experience and knowledge to the research on the same line as the participants. The researcher does not place oneself above or outside, but beside and close. So, the rigor is not about trying to ensure that the researcher does not influence the research, but about understanding the possible influence and opening this up to the reader. (Spence 2017.) That is why the researcher presented her own preunderstandings that might influence data collection and analysis and through them to results. In addition to this, the implementation of the analysis was described with examples and quotes so that the reader got an idea of the data-oriented nature of the results. (see Armour et al. 2009.)

In this study, bias was mitigated by avoiding leading questions in interviews and by reflecting the analysis with the participants and other researchers (Squires & Dorsen 2018). Credibility of the findings is partly about how other researchers find them trustworthy. There is a concept 'verisimilitude' which refers to credibility in hermeneutic studies. Verisimilitude includes how well the findings suit to one's own experiences and the experiences usually agreed in the society. (Charalambous & Kaite 2013.)

During this study, there was a reflective discussion about the findings with other researchers, nursing professionals, older people with dementia and their family members. During the research process, there was a lot of discussion with other researchers about the contents of the concept of spirituality and how the results were generated based on this qualitative data. Their perspectives were considered in the interpretation processes. In the second sub-study, the findings were sent to the participants through e-mail to give them a possibility to comment. All the participants who replied, agreed on the findings. This 'member checking' indicated that the findings fit the experiences of the participants (see Armour et al. 2009). In other sub-studies, the findings were at times presented to the nursing professionals

working in dementia care. They experienced that the results described the *life-world* of nursing care for older people with dementia. There was an open discussion with older people with dementia during the process whenever someone expressed an interest in talking about spirituality. During the research, the researcher worked as the manager of a nursing home for the older people and occasionally as a nurse in the care of people with dementia, so there were plenty of contacts. The preliminary results of the third and fourth sub-studies were presented for a group of family caregivers of older people who were offered a possibility to comment on them.

Considering different aspects of rigor (see Squires & Dorsen 2018) in this qualitative study are presented in table 9.

Table 9. Actions taken to ensure rigor.

ASPECT OF RIGOR	ACTIONS IN THIS RESEARCH
Credibility	Prolonged engagement with data: The researcher conducted all the interviews, transcribed them herself and was reading the manuscripts over repeatedly.
	Triangulation of data across participants: The participants represented three different groups: nursing professionals, older people with dementia and their family members.
	Peer debriefing: The study protocol and the findings were discussed with peer researchers during the process.
	Referential adequacy: The literature review was conducted to ensure broad knowledge of the earlier research in the field. The literature review was updated during the process.
	Member checks: The research group meetings were organized regularly. The articles were written in cooperation.
	Accuracy of the findings overall: The participants in the sub-study II found the results truthful to their lived experiences as the preliminary findings were sent to them for review. In sub-studies III and IV the findings were represented not to the participants but to other older people with dementia and their family members who confirmed that the findings were representative of their experiences.
Transferability	The findings were described in detail using quotes. The findings were reflected in the light of the research questions and earlier research.
	The participants and context were described so that the reader can draw conclusions about generalisability. Generalizing the findings was discussed.
Dependability	To ensure objectivity: The researcher reflected her own preunderstanding of the phenomenon and considered her own influence in research findings; in the interviews, leading questions were avoided.
	The interpretation processes were described in detail and examples of analysis were offered to make it possible for any other researcher to follow the protocol.
Confirmability	During the data interpretation, the process and the findings were shared and discussed with the research team.

6.4 Suggestions for future research

This study adds to the research evidence on supporting the spirituality of older people with dementia. Still, empirical research on supporting the spirituality of older people with dementia is sparse. Conducting this study raised many new questions for researching spirituality of older people with dementia.

First, older people living with dementia have been participants in few studies on spirituality. These have been mostly interview-studies or studies using quantitative methods. (Daly et al. 2019.) Due to the requirements of these methods of collecting the data, the participants have mostly been older people with mild to moderate dementia (Katsuno 2003; Chen et al. 2019). People with advanced dementia have been excluded from these studies because of their challenges in verbal communication (Camacho-Montaño et al. 2021). Information about supporting their spirituality has only been obtained through their family members, caregivers, and nursing professionals (Camacho-Montaño et al. 2021). In addition to this indirect information, it would be important to collect information from them, for example through observational methods.

Secondly, nursing professionals face challenges in addressing the spiritual needs of older people with dementia. This is the case especially when the disease has progressed, and verbal communication has become difficult. Intensive research should be conducted to develop suitable tools for measuring the spiritual needs of older people with dementia (Palmer et al. 2022; Britt et al. 2023). It was noted that not all nursing professionals feel comfortable in providing spiritual support in their work (see also Camacho-Montaño et al. 2021). It would be useful for them to have practical guidelines on how to support the spirituality of people with dementia in nursing practice.

Thirdly, spirituality is strongly connected to the surrounding culture (Britt et al. 2023). It would be important to study the spirituality of older people with dementia in different cultural environments and amid various religious traditions.

Fourth, this study used photography to support discussion on an abstract phenomenon. Based on this experience, it would be useful to utilize photography as a visual method more widely in research conducted with older people with dementia in the future. Photography could be used in the study of other abstract phenomena, when the aim is to understand the lived experiences of the participants. Regarding the phenomenon of spiritual support, photography is recommended to be used in data collection in the future. Using a professional in photographing was novel and is recommended because it was found to be a workable solution.

Fifth, from a hermeneutic-phenomenological starting point, understanding increases through each person's lived experiences (Crowther & Thomson 2022, p.5). More understanding is needed about how older people living with different stages of dementia experience spiritual support. The hermeneutic circle is endless, and the

interpretation of the phenomenon must continue to increase comprehensive understanding (Crowther & Thomson 2022, p.5). In this study, the phenomenon has been approached from the perspective of older people with dementia, their family members, and nursing professionals. These groups are key experiencers of the phenomenon. In the future, their stories could be interpreted within a hermeneutic framework, utilizing different methods of interpretation. In this study, understanding has been sought by utilizing Heidegger's philosophy and Ricoeur's theory of interpretation. The diversity of interpretations could be increased by approaching the phenomenon through other interpretive phenomenological approaches.

Sixth, the concept of spirituality has retained its vagueness and imprecision (Murgia et al. 2020). Although this dynamic variability partly belongs to the nature of the concept (Murgia et al. 2020), it is still necessary to analyse the meaning of the concept in different contexts. A common understanding of the concept, its nature and variations in changing multicultural environments creates the basis for all research into the phenomenon (Hellmann 2024).

Finally, the theory developed based on the research results is not ready and allencompassing but must be further developed. With the accumulation of lived experiences, new dimensions are discovered and the overall understanding increases within this hermeneutic circle.

6.5 Practical implications

Based on the findings of this study, the following implications are suggested for nursing, policymaking, education, and religious/spiritual communities.

Implications for nursing practice and administration

- Supporting the spirituality of older people with dementia can help them cope with the serious disease. It can help them in searching for meaning and purpose in life and give them hope and comfort. This descriptive theory offers a structured framework for nursing professionals to support the spirituality of older people with dementia in their caring and living environments.
- Nursing professionals need to pay attention to the spiritual needs of older people with dementia in care planning. To conduct this, assessing spiritual needs is essential. This study provides guidance in addressing spiritual needs.

- Some practical interventions were addressed to help nursing professionals in supporting the spirituality of older people with dementia as a part of nursing practice (Paper I).
- The study findings indicate that caring and living environment of older people can support them also spiritually. The physical, social and symbolic environment can guide nursing professionals in finding the individual ways of spiritual support. The environment is recommended to be designed so that the symbolism that brings meaning and purpose to the life of an older person with dementia is supporting those participating in the care and him/herself.
- The caring environment for older people with dementia is increasingly also their living environment. They live their own daily lives in that environment and interact with their environment constantly. Everything, including life itself, takes place in the environment. That is why attention should be paid to the different aspects of the environment both in nursing practice and in its administration.
- Supporting spirituality is an essential part of high-quality comprehensive care for people with dementia. This needs to be taken into account when planning care at the organizational level. Nursing management at different levels of the organization can encourage the nursing staff to support the spirituality of older people with dementia. The unit managers are in a central position in supporting and encouraging the nursing professionals in spiritual care.

Implications for policymaking

- Spiritual support needs to get more attention in social and health care in order to achieve the goal of the Global Action Plan on the Public Health response to dementia (World Health Organization 2017).
- The quality of nursing care for older people and the adequacy of nursing professionals have come up for discussion worldwide. Laws have also been drawn up on the required staffing. Older people with dementia have the right to respectful care and preservation of their dignity. Nursing professionals' well-being and willingness to work with older people is influenced by their experience of the quality of care they provide. Taking spiritual needs into account is part of high-quality nursing care, where the personality and humanity of an older person with dementia is respected. When implemented in nursing environments, spirituality can have two-way positive effects: both nurses and older people with dementia benefit.

The vulnerability of older people with dementia is still an important issue to consider in the social debate. This study found that older people with dementia can participate in research and thereby influence their own care in the future. Vulnerability does not mean that older people with dementia should be overprotected by isolating them from society (see Sanchini et al. 2022). On the contrary, supporting them in social participation is essential.

Implications for education

- Spirituality, broadly understood, is a part of humanity, and taking it into account is humane, understanding and compassionate care. With the increasing shortage of nursing professionals, the number of educated nurses in the care of older people with dementia is decreasing, and the nursing work is becoming task-oriented, where the person being cared for may be overshadowed by the procedures. Emphasizing spirituality in the education of nursing professionals, in guidance for nursing practice, and in organizations that provide care, brings out the person behind the illness. This is essential because a human beings have a need to be seen, accepted and appreciated as themselves.
- Supporting spirituality is part of comprehensive nursing care.
- Nursing professionals face spiritual needs of older people with dementia in their work. Including spiritual support in the basic education of nursing professionals is crucial to ensure that they have competence in addressing and meeting spiritual needs of older people with dementia.
- The descriptive theory offers nursing educators a framework for planning and conducting this education.

Implications for religious/ spiritual communities

- In the light of this study, older people living with dementia have a need to continue their spiritual lives. However, religious and other spiritual communities seem to need help in participating older people with dementia in their activities.
- The findings of this study can be used to encourage people in these organisations to engage people with dementia in their activities with the knowledge of their willingness to continue their spiritual life despite of cognitive decline.

- This study offers understanding of the diversity of spirituality among older people with dementia.
- This study also highlights importance of continuity and sense of safety that traditions enhance.

7 Conclusions

This study produced new way of understanding the life-world of older people with dementia in three levels: 1) The supporting perspective to the spirituality of older people with dementia is new and yet central from the caring point of view, 2) the role of the environment in supporting spirituality can be understood through the results of this research and 3) descriptive theory on supporting the spirituality of older people with dementia derived from the findings of this study offers novel understanding about the phenomenon.

The participants understood spirituality broadly, not only as religiosity, but as questions of meaning and purpose in life. As the core of humanity, the concept was present in all people's lives, and thus required attention also in the care of older people with dementia.

In advance, the health and social care sector needs to consider the increase in dementia and organizing the care in the future. Older people with dementia would largely benefit from spiritual support. This support does not require large financial investments. Nevertheless, it can contribute to increasing the well-being of older people with dementia. At the same time, it can also increase the nursing professionals' experience of the meaningfulness of their work by bringing new depth to encounters. This can benefit older people care in times of increasing labor shortage. Therefore, there is a need to know how the spirituality of older people with dementia can be supported.

Hermeneutic phenomenology was found to be a suitable background philosophy and methodical starting point for understanding the phenomenon. Interpreting the interview data and photographs from that starting point, the phenomenon was understood comprehensively.

The theory developed based on the results of this study provides a framework for spiritual support. In caring and living environments of older people living with dementia, nursing professionals can support the spirituality of older people by approaching them as valuable humans and from this basis by supporting their personal philosophy of life. The spiritual background and individual experiences of meaning in life determine whether this support is through religion, meaningful relationships, nature, or arts or through combination of them.

Nursing professionals can find out the spiritual needs of each older person with dementia by learning about their spiritual background and by listening to their verbal and non-verbal expression. Spiritual support is about searching meaning in life together. Caring and living environments can give nursing professionals clues about elements that people with dementia experience as ways to search for meaning in life. The environment can also be developed to support spirituality on that basis.

Altogether supporting spirituality needs to be considered for that people living with dementia get support they need to live a life with meaning and dignity as demanded in international strategies. In an ethically functioning society, humanity and people are taken care of. Every fragile and vulnerable individual is a human being and a member of society. This can be seen in how older people with dementia are valued in society and nursing. Supporting spirituality puts at the center the person, humanity, and humanely sustainable care in the multicultural and global world. Spirituality includes understanding human individuality and depth. In considering spirituality, the disease does not define the person. Older people with dementia need to be seen as themselves, just like all of us. Nursing professionals are privileged to see.

Acknowledgements

I conducted this study in the University of Turku, Faculty of Medicine, Department of Nursing Science in the Doctoral programme in Nursing Science. I was encouraged and supported in my research by so many people during this process that it is impossible to name all of them.

First, I would like to express my sincere gratitude to the organizations that provided financial support for my research. My deepest thanks go to the Betania Foundation, the Foundation for Nursing Education, and the State Governmental Funding (VTR) at Turku University Hospital. Your generous contributions have been invaluable in the completion of this dissertation.

I am especially grateful to my patient supervisors, Professor Riitta Suhonen, RN, PhD and Professor Andreas Charalambous RN, PhD. The circumstances of my life have not given me a strong self-esteem. Even though I knew I wanted to do research, I would never have taken a step towards doctoral studies without professor Riitta Suhonen's encouragement. Her expertise has always been clear. It is incredible how she has always managed to give the impression of being unhurried although I know her schedule is tight. She has made statements and commented on my manuscripts in a miraculously fast time frame. I could not have wished for anything more. Professor Andreas Charalambous gave me the inspiration to use new methods and even more: to dive deep into the theories and philosophies behind them. His expertise and creativity in the use of qualitative methods are in a class of their own. He challenged me to deeper interpretations. Both of my supervisors have always made it easy for me to turn to them when I have needed help. They both have given generously from their time and experience.

I want to thank the members of my follow-up committee, Professor Minna Stolt and Docent Matti Kamppinen. Dr Minna Stolt has been involved in my research project from the beginning as a co-writer and then as a member of my follow-up committee. Dr Matti Kamppinen has always taken time to comment on my proceedings. His insights from the perspective of study of religion have given me inspiration to consider for example the use of the concepts.

I am grateful to Markus Lahtinen who was doing amazing work as a photographer in this research project. In the photos, he managed to capture what

older people with dementia and their family members were reaching for. He had a talent of listening to people and seeing the environment from their perspective.

I wish to thank Norman Rickard for his excellent work as a language reviewer in all the publications of my dissertation. I have been amazed how his touch has improved the flow of my English texts.

I am grateful to researcher colleagues I have had a priviledge to meet during this process.

I am grateful to all the nursing professionals, older people with dementia and their family members who gave me their precious time and participated in this study. I know that my questions were not always easy to answer or even to understand but you were patient with me and gave me a lot. It was not only to have the interviews done for my study but having deep and touching conversations with amazingly wise people. I learnt a lot during the time we spent together and I am sincerely wishing you all the best in your lives.

I am grateful to the people with whom I have worked in older people care: My colleagues, who are warm-hearted professionals. To my predecessor, Piia Pitkäpaasi, who has made it possible for my research to progress even in challenging situations, and who herself is such an enviably productive person that it must have been painful for her to watch my slow progress towards becoming a doctor. To all the professionals in Mehiläinen, with whom I have been able to go through many challenges and successes together. To team leader Susanna, who has effectively done my work when I myself have focused on research. The world needs people like her. In addition, there are so many people in Mainiokoti Raisiontori and our organization, who have encouraged me to move forward by asking about the date of the karonka every single time we have met. You recognize yourselves.

I am grateful to all the inspiring people in my life, whose presence always sets my soul free: To my mother, who has always believed in me. She has been willing to sacrifice her time and make an effort so that I can complete my doctoral studies. To her mother, who has taught me about spirituality in her own humble way. To my beloved children Meri-Tuuli, Sini-Lumia and Nooa who are the cause of all my efforts. They have managed to be happy about my small successes along this journey and put up with mother hiding behind the laptop. There is no greater love than a mother's love for her children. To Minja, who has shown me that even a little girl can keep joy and love in her heart despite the circumstances of life. To my sister Katriina, on whom I have always been able to lean, and who has always been so sincerely glad of my successes. She has supported me with useful and practical advice in times of challenges. In the midst of her own hectic life, she has always been ready to help with practical matters as well, when I have organized my life as a single parent. Her positivity and joy is amazing. To my other sister Jasmiina. To my father who has taught me how to think differently.

I am so grateful to my friends Liisa and Sanni who have always been ready to help me to recover and relax. I am sure Liisa does not even know how important it was for me that she believed in me both professionally and as a person. She found me insecure, but gave me strength and confidence. Liisa's faith in my skills has always carried me. I trust with all my heart that whatever comes up in life, she will do everything she can to help. In Sanni, I have found a person whose thoughts run on the same track as mine. I am not sure whether that is a compliment or not. Our daily contact is essential to me. Sanni has an incredible creative ability to brighten up the whole spectrum of life with her black humor. I love it. There are no other friends like Liisa and Sanni. You are both so special to me.

Finally, I owe my deepest gratitude to my beloved Tomi who has lighted up my life, who has opened the eyes of my heart to see new depths. He has been with me on this journey both figuratively and concretely. I have been able to trust that whether I achieve my phD or not, he will stay with me. He has taken me out cycling from my dusty research chamber. He has been by my side in the ups and patiently waited in the downs. I have been able to rest by his side. Tomi knows my insecurities and always manages to remind me that I can hold my head up and trust myself. Thank you for being on my side and being the one I can lean on. You have supported me in more ways than you even realize.

The meaning and purpose of my life is in the people I love.

I am grateful to Him who has guided me on this journey and on all my journeys before, now and in the future. My life is in His hands.

Helsinki 26.9.2024 Kristiina Juudin



Kristiina Juudin RN, MNsc.

References

- Alzheimer's Association (2023). https://www.alz.org/alzheimers-dementia/what-is-dementia. Referred to 1.2.2023.
- Armour M, Rivaux S & Bell H. (2009). Using context to build rigor: application to two hermeneutic phenomenological studies. *Qualitative Social Work*, 8(1), 101–122.
- Aveyard B & Schofield P. (2002). Research notes: transcribing interviews in qualitative research takes time and effort. *Nursing Standard*, 16(25), 22.
- Baumbusch J, Kagan S & Melendez T. (2023). Celebrating and recollecting our impact: Announcing the 2022 IJOPN awards. *International Journal of Older People Nursing*, 18(5), 1–3. https://doiorg.ezproxy.utu.fi/10.1111/opn.12571.
- Beauchamp T & Childress J. (2019). *Principles of biomedical ethics* (Eighth edition.). New York: Oxford University Press.
- Berry D. (2005). Methodological pitfalls in the study of religiosity and spirituality. *Western Journal of Nursing Research*, 27(5), 628-647.
- Best M, Jones K, Washington J, Sullivan J, Kearney M & Puchalski C. (2022). Evaluation of the interprofessional spiritual care education curriculum in Australia. *Palliative and Supportive Care* 21(1), 65-73. https://doi.org/10.1017/S1478951522000244.
- Beuscher L & Beck C. (2008). A literature review of spirituality in coping with early-stage Alzheimer's disease. *Journal of Clinical Nursing*, 17(5A), 88–97. https://doiorg.ezproxy.utu.fi/10.1111/j.1365-2702.2007.02126.x.
- Beuscher L & Grando V. (2009). Challenges in conducting qualitative research with individuals with dementia. *Research in Gerontological Nursing*, 2(1), 6–11. https://doiorg.ezproxy.utu.fi/10.3928/19404921-20090101-04.
- Beuscher L & Grando V. (2009). Using Spirituality to Cope With Early-Stage Alzheimer's Disease. *Western Journal of Nursing Research*, 31(5), 583–598. https://doi.org/10.1177/0193945909332776.
- Beyea S & Nicoll L. (1997). Research corner. Qualitative and quantitative approaches to nursing research. *AORN Journal*, 66(2), 323–325. https://doi-org.ezproxy.utu.fi/10.1016/S0001-2092(06)62803-2.
- Biley F & Freshwater D. (1998). Spiritual care and the environment: a new paradigm for nursing? *Complementary Therapies in Nursing and Midwifery*, 4(4), 98-99. doi: 10.1016/s1353-6117(98)80041-3. PMID: 9830931.
- Bosco A., Schneider J, Coleston-Shields D & Orrell M. (2019). Dementia care model: Promoting personhood through co-production. *Archives of Gerontology & Geriatrics*, 81, 59–73. https://doi.org/10.1016/j.archger.2018.11.003.
- Braun V & Clarke V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. doi:10.1191/1478088706qp063oa.
- Brennan S & Doan T. (2023). Small-Scale Living Environments' Impact on Positive Behaviors and Quality of Life for Residents with Dementia. *Journal of Aging & Environment*, 37(2), 181–201. https://doi-org.ezproxy.utu.fi/10.1080/26892618.2022.2030845.

- Britt K, Richards K, Radhakrishnan K, Vanags-Louredo A, Park E, Gooneratne N & Fry L. (2023). Religion, Spirituality, and Coping During the Pandemic: Perspectives of Dementia Caregivers. *Clinical Nursing Research*, 32(1), 94–104. https://doi-org.ezproxy.utu.fi/10.1177/10547738221115239.
- Bruce A, Sheilds L & Molzahn A. (2011). Language and the (Im)possibilities of Articulating Spirituality. *Journal of Holistic Nursing*, 29(1), 44–52.
- Buck H. (2006). Spirituality: concept analysis and model development. *Holistic Nursing Practice*, 20(6), 288–292. https://doi.org/10.1097/00004650-200611000-00006.
- Buckley R. (2022). Ten steps for specifying saturation in qualitative research. *Social Science & Medicine*, 309, N.PAG. https://doi.org/10.1016/j.socscimed.2022.115217.
- Bugos E, Frasso R, True G, Adachi-Mejia A & Cannuscio C. (2014). Practical guidance and ethical considerations for studies using photo-elicitation interviews. *Preventing Chronic Disease*, 11(E189), 1-9. https://doi-org.ezproxy.utu.fi/10.5888/pcd11.140216.
- Bynum W & Varpio L. (2018). When I say ... hermeneutic phenomenology. *Medical Education*, 52(3), 252–253. https://doi-org.ezproxy.utu.fi/10.1111/medu.13414.
- Camacho-Montaño L, Pérez-Corrales J, Pérez-de-Heredia-Torres M, Martin-Pérez A, Güeita-Rodríguez J, Velarde-García J & Palacios-Ceña D. (2021). Spiritual Care in Advanced Dementia from the Perspective of Health Providers: A Qualitative Systematic Review. *Occupational Therapy International*, 11(24), 1–11. https://doi-org.ezproxy.utu.fi/10.1155/2021/9998480.
- Camicioli R. (2014). Diagnosis and differential diagnosis of dementia. In the book: Quinn, J. (Ed.). *Dementia, 1-13*. John Wiley & Sons, Incorporated.
- Campbell S, Greenwood M, Prior S, Shearer T, Walkem K, Young S, Bywaters D & Walker K. (2020). Purposive sampling: complex or simple? Research case examples. *Journal of Research in Nursing*, 25(8), 652–661. https://doi-org.ezproxy.utu.fi/10.1177/1744987120927206.
- Canda E. (1988). Spirituality, religious diversity, and social work practice. Social Casework (238-247).
- Carr T, Hicks-Moore S & Montgomery P. (2011). What's so big about the 'little things': A phenomenological inquiry into the meaning of spiritual care in dementia. *Dementia*, 10(3), 399–414.
- Carroll M. (2001). Conceptual models of spirituality. Social Thought, 20(1-2), 5-21.
- Chagas C, Martins L, Machado F, Zangari W & Galduróz J. (2023). Religious and secular spirituality: Methodological implications of definitions for health research. *Explore: The Journal of Science & Healing*, 19(1), 6–13. https://doi.org/10.1016/j.explore.2022.04.004.
- Charalambous A & Charalambous M. (2016). "I Lost My Image, the Image Others Know Me By": Findings from a Hermeneutic Phenomenological Study of Patients Living with Treatment-Induced Cutaneous Toxicities. *Research In Nursing & Health*, 39(3), 187-196. https://doiorg.ezproxy.utu.fi/10.1002/nur.21722.
- Charalambous A. (2014). Hermeneutic phenomenological interpretations of patients with head and neck neoplasm experiences living with radiation-induced xerostomia: the price to pay? *European Journal of Oncology Nursing*, 18(5), 512–520. https://doi.org/10.1016/j.ejon.2014.04.007.
- Charalambous A & Kaite C. (2013). Undergraduate nursing students caring for cancer patients: hermeneutic phenomenological insights of their experiences. *BMC Health Services Research* 13(1), 63. https://doi.org/10.1186/1472-6963-13-63.
- Charalambous A, Papadopoulos I. & Beadsmoore A. (2008). Ricoeur's hermeneutic phenomenology: an implication for nursing research. *Scandinavian Journal of Caring Sciences*, 22(4), 637-642. doi:10.1111/j.1471-6712.2007.00566.x.
- Charalambous A, Papadopoulos R. & Beadsmoore A. (2009). Towards a theory of quality nursing care for patients with cancer through hermeneutic phenomenology. *European Journal of Oncology Nursing*, 13(5): 350-360. https://doi.org/10.1016/j.ejon.2009.04.011.
- Chaudhury H, Cooke H, Cowie H & Razaghi L. (2017). The influence of the physical environment on residents with dementia in long-term care settings: A review of the empirical literature. *The Gerontologist*, 58(5), e325–e337.

- Chen H-C, Chan S, Yeh T-P, Huang Y-H, Chien I & Ma W-F. (2019). The Spiritual Needs of Community-Dwelling Older People Living With Early-Stage Dementia-A Qualitative Study. *Journal of Nursing Scholarship*, 51(2), 157-167.
- Chen A, Teng A, Zhao J, Asirot M & Turner A. (2022). The use of visual methods to support communication with older adults with cognitive impairment: A scoping review. *Geriatric Nursing*, 46(July2022), 52–60. https://doi-org.ezproxy.utu.fi/10.1016/j.gerinurse.2022.04.027.
- Clarke J. (2006). A discussion paper about "meaning" in the nursing literature on spirituality: an interpretation of meaning as "ultimate concern" using the work of Paul Tillich. *International Journal of Nursing Studies*, 43(7), 915–921.
- Clarke V & Braun V. (2017). Thematic analysis, *The Journal of Positive Psychology*, 12(3), 297-298. DOI: 10.1080/17439760.2016.1262613.
- Clarke C & Keady J. (2002). Getting down to brass tacks. A Discussion of data collection with people with dementia. In: Wilkinson H. (ed.). The perspectives of people with dementia: research methods and motivations. London: Jessica Kingsley, pp. 25-46.
- Cohen M, Holley L, Wengel S & Katzman R. (2012). A Platform for Nursing Research on Spirituality and Religiosity: Definitions and Measures. Western Journal of Nursing Research, 34(6): 795-817.
- Connell M. (2012). Spirituality and spiritual care from a Careful Nursing perspective. *Journal of Nursing Management*, 20(8), 990–1001. https://doi-org.ezproxy.utu.fi/10.1111/j.1365-2834.2012.01462.x.
- Conway E, MacEachen E, Middleton L & McAiney C. (2023). Use of adapted or modified methods with people with dementia in research: A scoping review. *Dementia*, 22(8), 1994–2023. https://doiorg.ezproxy.utu.fi/10.1177/14713012231205610.
- Conway M. (1985). Toward greater specificity in defining nursing's metaparadigm. *Advances in Nursing Science*, 7(4), 73–81. https://doi-org.ezproxy.utu.fi/10.1097/00012272-198507000-00010
- Cooper D. (1996). Heidegger. Thinkers of Our Time. Bloomsbury Publishing Plc., London, Great Britain.
- Counts N, Nandi A, Seligman B & Tortorice D. (2021). Dementia storm on the horizon: The rising incidence of dementia around the world calls for global collaboration and decisive financing. *Finance and Development*, 58(4), 54-57.
- Crowther S & Thomson G. (Eds.). (2022). Hermeneutic Phenomenology in Health and Social Care Research (1st ed.). Routledge. https://doi-org.ezproxy.utu.fi/10.4324/9781003081661.
- Curtis A. & Keeler C. (2022). Interpretive Methodologies in Qualitative Nursing Research. *AJN American Journal of Nursing*, 122(10), 45–49. https://doi.org/10.1097/01.NAJ.0000890224.65902.0a.
- Dalby P, Sperlinger D & Boddington S. (2012). The lived experience of spirituality and dementia in older people living with mild to moderate dementia. *Dementia*, 11(1), 75–94.
- Daly L & Fahey-McCarthy E. (2014). Attending to the spiritual in dementia care nursing. *British Journal of Nursing*, 23(14), 787–791. https://doi-org.ezproxy.utu.fi/10.12968/bjon.2014.23.14.787.
- Daly L, Fahey-McCarthy E & Timmins F. (2019). The experience of spirituality from the perspective of people living with dementia: A systematic review and meta-synthesis. *Dementia*, 18(2):448-470. doi:10.1177/1471301216680425.
- Darbyshire P & Oerther S. (2021). Heidegger and parenthood: A theoretical and methodological shift from instrumental to ontological understanding. *Journal of Child Health Care*, 25(4), 523–533. https://doi.org/10.1177/1367493520965836.
- Denzin N. & Lincoln Y. (eds) (2005). The Sage Handbook of Qualitative Research (3rd ed.). London: Sage.
- Diaz-Gil A, Brooke J, Kozlowska O, Jackson D, Appleton J & Pendlebury S. (2023). A human rights-based framework for qualitative dementia research. *Nursing Ethics*, 30(7/8), 1138–1155. https://doi-org.ezproxy.utu.fi/10.1177/09697330231161687.
- Dodgson J. (2019). Reflexivity in Qualitative Research. *Journal of Human Lactation*, 35(2), 220–222. https://doi.org/10.1177/0890334419830990.

- Dowling M & Cooney A. (2012). Research approaches related to phenomenology: negotiating a complex landscape. *Nurse Researcher*, 20(2), 21-27.
- Dröes R.-M, Boelens-Van Der Knoop E, Bos J, Meihuizen L, Ettema T, Gerritsen D, Hoogeveen F, De Lange J & SchöLzel-Dorenbos C. (2006). Quality of life in dementia in perspective: An explorative study of variations in opinions among people with dementia and their professional caregivers, and in literature. *Dementia*, *5*(4), 533–558. https://doi.org/10.1177/1471301206069929.
- Dunn K & Robinson-Lane S. (2020). A Philosophical Analysis of Spiritual Coping. *Advances in Nursing Science*, 43(3), 239–250. https://doi.org/10.1097/ANS.0000000000000323.
- Edvardsson D, Sandman P & Borell L. (2014). Implementing national guidelines for person-centered care of people with dementia in residential aged care: effects on perceived person-centeredness, staff strain, and stress of conscience. *International Psychogeriatrics*, 26(7), 1171–1179. https://doi.org/10.1017/S1041610214000258.
- Emblen J. (1992). Religion and spirituality defined according to current use in nursing literature. Journal of Professional Nursing: Official Journal of the American Association of Colleges of Nursin., 8(1), 41–47. https://doi.org/10.1016/8755-7223(92)90116-g.
- Ennis E, Kazer M & Wallace M. (2013). The Role of Spiritual Nursing Interventions on Improved Outcomes in Older Adults With Dementia. *Holistic Nursing Practice*, 27(2), 106-113.
- Feddersen E & Lüdtke I. (2014). Lost in space: Architecture and Dementia, Berlin, Boston: Birkhäuser. Finnish National Board on Research Integrity TENK. (2023). The Finnish code of conduct for research integrity and procedures for handling alleged violations of research integrity in Finland Guideline of the Finnish National Board on Research Integrity TENK 2023. Publications of the Finnish National Board on Research Integrity TENK 4/2023, Helsinki, Finland.
- Fleming R, Bennett K & Zeisel J. (2023). Values and Principles Informing Designs for People Living With Dementia—an Emerging International Consensus. *Journal of Aging & Environment*, 37(3), 245–254. https://doi-org.ezproxy.utu.fi/10.1080/26892618.2022.2062806.
- Frisch N & Rabinowitsch D. (2019). What's in a Definition? Holistic Nursing, Integrative Health Care, and Integrative Nursing: Report of an Integrated Literature Review. *Journal of Holistic Nursing*, 37(3), 260–272. https://doi.org/10.1177/0898010119860685.
- Gall T, Malette J & Guirguis-Younger M. (2011). Spirituality and Religiousness: A Diversity of Definitions. *Journal of Spirituality in Mental Health*, 13(3), 158–181. https://doi.org/10.1080/19349637.2011.593404.
- Gallagher A & Warren R. (2019). Ethical aspects of Individualised Care. In Suhonen R, Stolt M & Papastavrou E. (Eds.) Individualized care. Theory, measurement, research and practice. Springer International Publishing AG, part of Springer Nature, Switzerland, pp. 39-51.
- Garrett B. (2021). Divinity in nursing: The complexities of adopting a spiritual basis for care. *Nursing Philosophy*, 22(3), 1–9. https://doi.org/10.1111/nup.12355.
- Geanellos R. (1998). Hermeneutic philosophy. Part I: implications of its use as methodology in interpretive nursing research. *Nursing Inquiry*, 5(3), 154–163.
- Geanellos R. (2000). Exploring Ricoceur's hermeneutic theory of interpretation as a method of analysing research texts. *Nursing Inquiry*, 7(2), 112–119. https://doiorg.ezproxy.utu.fi/10.1046/j.1440-1800.2000.00062.x.
- Gibson G, Quirke M & Lovatt M. (2022). The role of environmental design in enabling intergenerational support for people with dementia what lessons can we learn from Japan. Working with Older People: Community Care Policy & Practice, 26(3), 226–237. https://doiorg.ezproxy.utu.fi/10.1108/WWOP-12-2021-0064.
- Graham M, Farina F, Ritchie C, Lawlor B & Naci L. (2022). Fear of Dementia and the Obligation to Provide Aggregate Research Results to Study Participants. *Cambridge Quarterly of Healthcare Ethics* 31(4), 498–505.
- Graneheim U & Lundman B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105-112. https://doi.org/10.1016/j.nedt.2003.10.001.

- Green B, Johnson C & Adams A. (2006). Writing narrative literature reviews for peer-reviewed journals: secrets of the trade. *Journal of Chiropractic Medicine*, 5(3), 101–117.
- Guest G, MacQueen K & Namey E. (2012). Introduction to applied thematic analysis, pp. 3-20. SAGE Publications, Inc., https://dx.doi.org/10.4135/9781483384436.
- Gullick J & West S. (2020). Heideggerian hermeneutic phenomenology as method: modelling analysis through a meta-synthesis of articles on Being-towards-death. *Medicine, Health Care & Philosophy*, 23(1), 87–105. https://doi.org/10.1007/s11019-019-09911-9.
- Ham A. (2021). First generation immigrant and native nurses enacting good care in a nursing home. *Nursing Ethics*, 28(3), 402–413. https://doi-org.ezproxy.utu.fi/10.1177/0969733020921487.
- Hardwick L. (2017). Paul Ricoeur's theory of interpretation adapted as a method for narrative analysis to capture the existential realities expressed in stories from people living with Multiple Sclerosis. *Qualitative Social Work*, 16(5), 649–663. https://doi.org/10.1177/1473325016638423.
- Harper D. (2002). Talking about pictures: A case for photo elicitation. *Visual Studies, 17*(1), 13–26. https://doi.org/10.1080/1472586022 0137345.
- Haufe M, Leget C, Potma M & Teunissen S. (2024). Better spiritual support for people living with early stage dementia: Developing the diamond conversation model. *Dementia*, 23(1), 91–108. https://doi-org.ezproxy.utu.fi/10.1177/14713012231213907.
- Head A, Ellis-Caird H, Rhodes L & Mengoni S. (2021). "It was really good, she sort of took some words what happened, like what I would say": Adapting dyadic interview techniques to capture the stories of marginalised voices in research. *Qualitative Methods in Psychology Bulletin*, 31, 35–44. https://doi-org.ezproxy.utu.fi/10.53841/bpsqmip.2021.1.31.35.
- Heidegger M. (2014). Hölderlin and the Essence of Poetry (1959). In *The Paul De Man Notebooks* (pp. 171–182). United Kingdom: Edinburgh University Press. https://doi.org/10.3366/edinburgh/9780748641048.003.0016.
- Hellman A. (2024). The Concept Analysis: An Effective and Important Starting Point in Nursing Research. *Journal of Radiology Nursing*, 43(1), 11–14. https://doiorg.ezproxy.utu.fi/10.1016/j.jradnu.2023.12.001.
- Hellström I, Nolan M, Nordenfelt L & Lundh U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14(5):608-19. doi: 10.1177/0969733007080206.
- Hennink M, Kaiser B & Marconi V. (2017). Code Saturation Versus Meaning Saturation: How Many Interviews Are Enough? *Qualitative Health Research*, 27(4), 591–608. https://doi.org/10.1177/1049732316665344.
- Hettema T. (2014). Autonomy and its vulnerability: Ricoeur's view on justice as a contribution to care ethics. *Medicine, Health Care & Philosophy*, 17(4), 493–498. https://doiorg.ezproxy.utu.fi/10.1007/s11019-013-9532-y.
- Hirakawa Y, Yajima K, Chiang C & Aoyama A. (2020). Meaning and practices of spiritual care for older people with dementia: experiences of nurses and care workers. *Psychogeriatrics*, 20(1), 44–40
- Ho K, Chiang V & Leung D. (2017). Hermeneutic phenomenological analysis: the 'possibility' beyond 'actuality' in thematic analysis. *Journal of Advanced Nursing*, 73(7), 1757–1766. https://doi.org/10.1111/jan.13255.
- Holloway I. (2017). *Qualitative research in nursing and healthcare* (Fourth edition.). Chichester, England: Wiley Blackwell.
- Holm G. (2020). 'Photography as a research method', in Patricia Leavy (ed.), *The Oxford Handbook of Qualitative Research*, 2nd edn, Oxford Handbooks, online edn. Oxford Academic. https://doi.org/10.1093/oxfordhb/9780190847388.013.26, accessed 16 Aug. 2023.
- Hougham G. (2005). Waste not, want not: Cognitive impairment should not preclude research participation. *American Journal of Bioethics*, 5(1), 36–37.
- Hughes J. (2020). Personhood and Religion in People with Dementia. In the book: Coles, A. & Collicutt, J. *Neurology and religion*. Cambridge University Press.

- Idler E. (2022). Is Secularization an Age-Related Process? *The International Journal of Aging and Human Development*, 94(1), 8–22. https://doi.org/10.1177/00914150211027547.
- Il S, So Y & Jin S. (2017). Evolutionary Concept Analysis of Spirituality. *Journal of Korean Academy of Nursing*, 47(2), 242–256.
- Infofinland. (2022). Cultures and religions in Finland. https://www.infofinland.fi/en/information-about-finland/cultures-and-religions-in-finland. Referred to 26.4.2022.
- James D & Komnenich P. (2021). Dilthey's philosophy and methodology of hermeneutics: An approach and contribution to nursing science. *Nursing Philosophy*, 22(3), e12353. https://doiorg.ezproxy.utu.fi/10.1111/nup.12353.
- Jewell A. (Ed.). (2003). Ageing, spirituality and well-being. Jessica Kingsley Publishers.
- Johansson K, Borell L & Rosenberg L. (2022). Qualities of the environment that support a sense of home and belonging in nursing homes for older people. *Ageing & society*, 42(1), 157–178.
- Johnson R, Tilghman J, Davis-Dick L & Hamilton-Faison B. (2006). A historical overview of spirituality in nursing. *ABNF Journal*, 17(2), 60–62.
- Johnston B, Lawton S, McCaw C, Law E, Murray J, Gibb J, Pringle J, Munro G & Rodriguez C. (2016). Living well with dementia: enhancing dignity and quality of life, using a novel intervention, Dignity Therapy. *International Journal of Older People Nursing*, 11(2), 107–120. https://doi.org/10.1111/opn.12103.
- Jolley D, Benbow S, Grizzell M, Willmott S, Bawn S & Kingston, P. (2010). Spirituality and faith in dementia. *Dementia*, 9(3), 311–325. https://doi.org/10.1177/1471301210370645.
- Jutkowitz E, Kane R, Gaugler J, MacLehose R, Dowd B & Kuntz K. (2017). Societal and Family Lifetime Cost of Dementia: Implications for Policy. *Journal of American Geriatrics Society*, 65(10), 2169-2175.
- Kangasniemi M, Utriainen K, Ahonen S, Pietilä A, Jääskeläinen P & Liikanen E. (2013). Kuvaileva kirjallisuuskatsaus: Eteneminen tutkimuskysymyksestä jäsennettyyn tietoon/Narrative literature review: From a research question to structured knowledge. *Hoitotiede*, 25(4), 291-301.
- Karlawish J, Cary M, Rubright J & Tenhave T. (2008). How redesigning AD clinical trials might increase study partners' willingness to participate. *Neurology*, 71(23), 1883–1888. https://doi.org/10.1212/01.wnl.0000336652.05779.ea.
- Katsuno T. (2003). Personal spirituality of persons with early-stage dementia: is it related to perceived quality of life? *Dementia: the International Journal of Social Research and Practice*, 2(3), 315–335.
- Kaufman Y, Anaki D, Binns M & Freedman M. (2007). Cognitive decline in Alzheimer disease. *Neurology*, 68 (18), 1509-1514. doi: 10.1212/01.wnl.0000260697.66617.59.
- Kim H. (1992). Structuring the Nursing Knowledge System: A Typology of Four Domains. In the book: Leslie H. Nicoll (ed.) Perspectives on Nursing theory, pp. 134-142. J.B. Lippincott Company, Philadelphia.
- Kim H. (2010). The nature of theoretical thinking in nursing (3rd ed.). Springer Pub. Co.
- King U. (2003). The dance of Life. Spirituality, Aging and Human Flourishing. In a book: Ageing, Spirituality and Well-Being, edited by Albert Jewell. Jessica Kingsley Publishers, 2003. ProQuest Ebook Central, http://ebookcentral.proquest.com/lib/kutu/detail.action?docID=290848, pp. 124-142.
- Kirkland K, Fortuna M, Kelson E & Phinney A. (2014). Music Therapy and Spiritual Care for Persons with Dementia: A Mixed-Methods Study/Musicothérapie et soins spirituels auprès de personnes atteintes de démence: étude à méthodologie mixte. *Canadian Journal of Music Therapy*, 20(1), 10-37. https://www.proquest.com/scholarly-journals/music-therapy-spiritual-care-persons-with/docview/1562002593/se-2?accountid=14774.
- Kowe A, Köhler S, Klein O, Lüthje C, Kalzendorf J, Weschke S & Teipel S. (2022). Stakeholder involvement in dementia research: A qualitative approach with healthy senior citizens and providers of dementia care in Germany. *Health & Social Care in the Community*, 30(3), 908–917. https://doi-org.ezproxy.utu.fi/10.1111/hsc.13238.

- Kristensson Uggla B. (2022). What makes us human? Exploring the significance of Ricoeur's ethical configuration of personhood between naturalism and phenomenology in health care. *Nursing Philosophy*, 23(3), 1–7. https://doi-org.ezproxy.utu.fi/10.1111/nup.12385.
- Lambert N, Stillman T & Fincham F. (2013). Autobiographical narratives of spiritual experiences: Solitude, tragedy, and the absence of materialism. *Journal of Positive Psychology*, 8(4), 273–279. https://doi-org.ezproxy.utu.fi/10.1080/17439760.2013.789119.
- Lazenby J. (2010). On "spirituality," "religion," and "religions": A concept analysis. *Palliative and Supportive Care*, 8(4), 469-476. doi:10.1017/S1478951510000374.
- Leese J, Li L, Nimmon L, Townsend A & Backman C. (2021). Moving Beyond "Until Saturation Was Reached": Critically Examining How Saturation Is Used and Reported in Qualitative Research. *Arthritis Care & Research*, 73(9), 1225–1227.
- Lindseth A & Norberg A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences*, 18(2), 145–153. https://doi-org.ezproxy.utu.fi/10.1111/j.1471-6712.2004.00258.x.
- Lindseth A & Norberg A. (2022). Elucidating the meaning of life world phenomena. A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences*, *36*(3), 883–890. https://doi.org/10.1111/scs.13039.
- Linzer N. (2006). Spirituality and ethics in long-term care. *Journal of Religion & Spirituality in Social Work.*, 25(1), 87–106.
- MacKinlay E. (2001), p. 52. The Spiritual Dimension of Ageing. London: Jessica Kingsley Publishers.
 MacKinlay E & Trevitt C. (2010). Living in aged care: Using spiritual reminiscence to enhance meaning in life for those with dementia. *International Journal of Mental Health Nursing*, 19(6), 394-401. https://doi-org.ezproxy.utu.fi/10.1111/j.1447-0349.2010.00684.x.
- Mackinlay E & Trevitt C. (2015). Facilitating Spiritual Reminiscence for Older People with Dementia: A Learning Guide. Jessica Kingsley Publishers.
- Mahlungulu S & Uys L. (2004). Spirituality in nursing: An analysis of the concept. *Curationis*, 27(2), 15-26. https://doi.org/10.4102/curationis.v27i2.966.
- McBrien B. (2006). Spirituality. A concept analysis of spirituality. *British Journal of Nursing*, 15(1), 42–45. https://doi.org/10.12968/bjon.2006.15.1.20309.
- McGee J, Zhao H, Myers D & Seela Eaton H. (2018). Spiritual Diversity and Living with Early-Stage Dementia. *Clinical Gerontologist*, 41(3), 261–267. https://doiorg.ezproxy.utu.fi/10.1080/07317115.2017.1393478.
- McSherry W & Cash K. (2004). The language of spirituality: an emerging taxonomy. *International Journal of Nursing Studies*, 41(2), 151–161.
- Merriam S & Tisdell E (2015). *Qualitative research: A guide to design and implementation*. John Wiley & Sons, Incorporated.
- Missel M & Birkelund R. (2020). Ricoeur's narrative philosophy: A source of inspiration in critical hermeneutic health research. *Nursing Philosophy*, 21(2), 1–6. https://doiorg.ezproxy.utu.fi/10.1111/nup.12254.
- Mlinar Reljić N, Fekonja Z, Kmetec S, McSherry W, Kores Plesničar B & Pajnkihar M. (2021). Family members' experiences with the spiritual care of older people living with dementia in nursing homes: A phenomenological hermeneutical study. *Nursing Open*, 8(6), 2932–2941. https://doiorg.ezproxy.utu.fi/10.1002/nop2.1001.
- Mmako N, Courtney-Pratt H & Marsh P. (2020). Green spaces, dementia and a meaningful life in the community: A mixed studies review. *Health & Place*, 63(May 2020), N.PAG. https://doi.org/10.1016/j.healthplace.2020.102344.
- Morgan D, Ataie J, Carder P & Hoffman K. (2013). Introducing Dyadic Interviews as a Method for Collecting Qualitative Data. *Qualitative Health Research*, 23(9), 1276–1284. https://doi.org/10.1177/1049732313501889.
- Morse J. (1991). Qualitative nursing Research: a free-for-all? In Morse J (Ed). *Qualitative Nursing Research: A Contemporary Dialogue*. Revised edition. Sage Publications, Newbury Park CA.

- MSAH (Finnish Ministry of Social Affairs and Health). STM (Sosiaali- ja Terveysministeriö). (2020). Laatusuositus hyvän ikääntymisen turvaamiseksi ja palvelujen parantamiseksi 2020–2023: Tavoitteena ikäystävällinen Suomi. Sosiaali- ja terveysministeriön julkaisuja 2020:29.
- MSAH (Finnish Ministry of Social Affairs and Health). STM (Sosiaali- ja Terveysministeriö). (2024). Laatusuositus aktiivisen ja toimintakykyisen ikääntymisen ja kestävien palvelujen turvaamiseksi 2024–2027. Sosiaali- ja terveysministeriön julkaisuja 2024:4.
- Murgia C, Notarnicola I, Rocco G & Stievano A. (2020). Spirituality in nursing: A concept analysis. *Nursing Ethics*, 27(5), 1327–1343.
- Murgia C, Notarnicola I, Caruso R, De Maria M, Rocco G & Stievano A. (2022). Spirituality and Religious Diversity in Nursing: A Scoping Review. *Healthcare*, 10(9), 1661. https://doiorg.ezproxy.utu.fi/10.3390/healthcare10091661.
- Narayanasamy A. (2004). The puzzle of spirituality: a guide to practical assessment. *British Journal of Nursing*, 13(19), 1140–1145.
- Nightingale F, Skretkowicz V & Nightingale F. (2010). Florence Nightingale's Notes on nursing what it is and what it is not & Notes on nursing for the labouring classes; commemorative edition with commentary. New York: Springer.
- Nyholm L, Salmela S, Nyström L & Koskinen C. (2018). Sustainability in care through an ethical practice model. *Nursing Ethics*, 25(2), 264–272. https://doi-org.ezproxy.utu.fi/10.1177/0969733017714303.
- Newman M. (1992). Nursing's theoretical evolution. In the book: Leslie H. Nicoll (ed.) *Perspectives on Nursing theory*, pp. 77-84. J.B. Lippincott Company, Philadelphia.
- O'Connor C, Liddle J, O'Reilly M, Meyer C, Cartwright J, Chisholm M, Conway E, Fielding E, Fox A, MacAndrew M, Schnitker L, Travers C, Watson K, While C & Bail K. (2022). Advocating the rights of people with dementia to contribute to research: Considerations for researchers and ethics committees. *Australasian Journal on Ageing*, 41(2), 309–313. https://doiorg.ezproxy.utu.fi/10.1111/ajag.13023.
- O'Reilly M, Fetherstonhaugh D, McMaster M, Moyle W, Fielding E & Beattie E. (2019). Supporting autonomy of nursing home residents with dementia in the informed consent process. *Dementia*, 18(7/8), 2821–2835. https://doi-org.ezproxy.utu.fi/10.1177/1471301218761240.
- Oakes L, Ewald D, Orsini M & Strac, R. (2022). The Photovoice Decision Tree: Legal Considerations and Ethical Implications for Photographs and Captions. *Health Promotion Practice*, 23(2), 250–261. https://doi-org.ezproxy.utu.fi/10.1177/15248399211053892
- Ødbehr L, Hauge S, Danbolt L & Kvigne K. (2017). Residents' and caregivers' views on spiritual care and their understanding of spiritual needs in persons with dementia: A meta-synthesis. *Dementia* (14713012), 16(7), 911–929. https://doi-org.ezproxy.utu.fi/10.1177/1471301215625013.
- OED Online. (2021). "spirituality, n." "religion, n." Oxford University Press, September 2021. Web. 5 November 2021.
- Olmos-Vega F, Stalmeijer R, Varpio L & Kahlke R. (2023). A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Medical Teacher*, 45(3), 241–251. https://doi.org/10.1080/0142159X.2022.2057287.
- Paley J. (2014) Heidegger, lived experience and method. *Journal of Advanced Nursing* 70(7), 1520–1531. doi: 10.1111/jan.12324
- Palmer J, Hilgeman M, Balboni T, Paasche-Orlow S & Sullivan J. (2022). Spiritual Experience of Dementia From the Health Care Provider Perspective: Implications for Intervention. *Gerontologist*, 62(4), 556–567. https://doi-org.ezproxy.utu.fi/10.1093/geront/gnab134.
- Petersson A, Sandin G & Liljas M. (2016). Room of silence: an explorative investigation of design students' redesign of an arena for reflection and existential meaning-making. *Mortality*, 21(2), 130–148. https://doi.org/10.1080/13576275.2015.1046825.
- PEW Research Center (2019). Social media fact sheet. Retrieved 15.4.2024 from: https://www.pewresearch.org/internet/fact-sheet/social-media/.

- Phillippi J & Lauderdale J. (2018). A Guide to Field Notes for Qualitative Research: Context and Conversation. *Qualitative Health Research*, 28(3), 381–388. https://doiorg.ezproxy.utu.fi/10.1177/1049732317697102.
- Phillipson L & Hammond A. (2018). More Than Talking: A Scoping Review of Innovative Approaches to Qualitative Research Involving People with Dementia. *International Journal of Qualitative Methods*, 17, 1-13.
- Piedmont R. (1999). Does spirituality represent the sixth factor of personality? Spiritual transcendence and the fve-factor model. *Journal of Personality*, 67(6), 985–1013. https://doi.org/10.1111/1467-6494.00080.
- Pratt R. (2001). Nobody's ever asked how I feel. In book: Wilkinson, H. (Ed.). *The perspectives of people with dementia: Research methods and motivations*. Jessica Kingsley Publishers.
- Prince M, Knapp M & Guerchet M. (2014). Dementia UK (Second edition): Update Alzheimer's Society.
- Racine E & Bracken-Roche D. (2019). Enriching the concept of vulnerability in research ethics: An integrative and functional account. *Bioethics*, 33:19-34.
- Ramezani M, Ahmadi F, Mohammadi E & Kazemnejad A. (2014). Spiritual care in nursing: A Concept Analysis. *International Nursing Review 61*(2), 211-219. https://doiorg.ezproxy.utu.fi/10.1111/inr.12099.
- Ranse J, Arbon P, Cusack L, Shaban R. & Nicholls D. (2020). Obtaining individual narratives and moving to an intersubjective lived-experience description: a way of doing phenomenology. *Oualitative Research*, 20(6), 945–959. https://doi.org/10.1177/1468794120905988.
- Ray M & Locsin R. (2023). Toward an adequate understanding of phenomenological and hermeneutic-phenomenological nursing research. *Nursing & Health Sciences*, 25(1), 3–8. https://doiorg.ezproxy.utu.fi/10.1111/nhs.13015.
- Reagan C. (1996). Paul Ricoeur. His life and his work. The University of Chicago Press, Chicago, USA. Reid B & O'Brien L. (2021). The psychological effects of caring for a family member with dementia. *Nursing Older People*, 33(6), 21–27. https://doi.org/10.7748/nop.2021.e1295.
- Reinert K & Koenig H. (2013) Re-examining definitions of spirituality in nursing research. *Journal of Advanced Nursing* 69(12), 2622–2634. doi: 10.1111/jan.12152.
- Renn B, Wool J & Belza B. (2021). A Typical Week with Mild Cognitive Impairment, *The Gerontologist*, 61(7), 1095–1106. https://doi.org/10.1093/geront/gnab008.
- Ribaudo A & Takahashi M. (2008). Temporal trends in spirituality research: A meta-analysis of journal abstracts between 1944 and 2003. *Journal of Religion, Spirituality & Aging*, 20(1-2), 16-28. doi:10.1080/15528030801921972.
- Ricoeur P. (1976). Interpretation Theory. Discourse and the surplus of meaning. Texas Christian University Press, Fort Worth, TX.
- Ricoeur P. (1981). Hermeneutics and the Human Sciences. University Press, Cambridge.
- Rogers M. (1988). Nursing Science and Art: A Prospective. *Nursing Science Quarterly*, 1(3), 99–101. https://doi.org/10.1177/089431848800100304.
- Rogers M. (1992). Nursing Science and the Space Age. *Nursing Science Quarterly*, 5(1), 27–34. https://doi.org/10.1177/089431849200500108.
- Rogers M. (1994). The Science of Unitary Human Beings: Current Perspectives. *Nursing Science Quarterly*, 7(1), 33–35. https://doi.org/10.1177/089431849400700111.
- Rogers M. (2016). Spiritual dimensions of advanced nurse practitioner consultations in primary care through the lens of availability and vulnerability. A hermeneutic enquiry. University of Huddersfield.
- Ryan E, Martin L & Beaman A. (2005). Communication strategies to promote spiritual well-being among people with dementia. *Journal of Pastoral Care and Counseling*, 59(1-2), 43-55. doi: 10.1177/154230500505900105. PMID: 15943144.

- Rykkje L, Eriksson K & Raholm M-B. (2013). Spirituality and caring in old age and the significance of religion a hermeneutical study from Norway. *Scandinavian Journal of Caring Sciences*, 27(2), 275–284.
- Rykkje L, Morland M, Ferstad K & Kuven B. (2023). A qualitative hermeneutical understanding of spiritual care in old age when living in a nursing home: The residents' voices. Journal of Clinical Nursing (John Wiley & Sons, Inc.), 32(21/22), 7846–7859. https://doiorg.ezproxy.utu.fi/10.1111/jocn.16855.
- Salazar H & Nicholls R. (Eds.). (2018). The philosophy of spirituality: Analytic, continental and multicultural approaches to a new field of philosophy. BRILL.
- Sanchini V, Sala R & Gastmans C. (2022). The concept of vulnerability in aged care: a systematic review of argument-based ethics literature. *BMC Medical Ethics*, 23(1), 1–20. https://doiorg.ezproxy.utu.fi/10.1186/s12910-022-00819-3.
- Sarter B. (1988). Philosophical sources of nursing theory. Nursing Science Quarterly, 1(2), 52-59.
- Sarter B. (1992). Philosophical Sources of Nursing Theory. In: Nicoll, L. (ed.) Perspectives on Nursing Theory. 2th ed. J.B. Lippincott Company, Pennsylvania. pp. 147-156.
- Sataloff R, Bush M, Chandra R, Chepeha D, Rotenberg B, Fisher E, Goldenberg D, Hanna E, Kerschner J, Kraus D, Krouse J, Li D, Link M, Lustig L, Selesnick S, Sindwani R, Smith R, Tysome J, Weber P & Welling D. (2021). Systematic and Other Reviews: Criteria and Complexities. *Ear, Nose & Throat Journal*, 100(6), 403–406. https://doi.org/10.1177/01455613211025937.
- Scott Barss K. (2020). Spiritual care in holistic nursing education: A spirituality and health elective rooted in T.R.U.S.T. And contemplative education. *Journal of Holistic Nursing*, 38(1), 122-130. https://doi-org.ezproxy.utu.fi/10.1177/0898010119889703.
- Seetharaman K, Shepley M. & Cheairs C. (2021). The saliency of geographical landmarks for community navigation: A photovoice study with persons living with dementia. *Dementia*, 20(4), 1191–1212. https://doi.org/10.1177/1471301220927236.
- Sessanna L, Finnell D & Jezewski M. (2007). Spirituality in Nursing and Health-Related Literature: A Concept Analysis. *Journal of Holistic Nursing*, 25(4), 252–262. https://doi.org/10.1177/0898010107303890.
- Simms K. (2003). Paul Ricoeur. London; Routledge. https://doi.org/10.4324/9780203165508
- Simonÿ C, Specht K, Andersen I, Johansen K, Nielsen C & Agerskov H. (2018). A Ricoeur-Inspired Approach to Interpret Participant Observations and Interviews. *Global Qualitative Nursing Research*, 5, 2333393618807395–2333393618807395. https://doi.org/10.1177/2333393618807395.
- Singsuriya P. (2015). Nursing researchers' modifications of Ricoeur's hermeneutic phenomenology. *Nursing Inquiry*, 22(4), 348–358. https://doi-org.ezproxy.utu.fi/10.1111/nin.12098.
- Smythe L & Spence D. (2022). Nurturing a Spirit of Attuning-to. In Crowther, S., & Thomson, G. (Eds.). *Hermeneutic Phenomenology in Health and Social Care Research* (1st ed.), pp. 21-36. Routledge. https://doi-org.ezproxy.utu.fi/10.4324/9781003081661.
- So H, Mackenzie L, Chapparo C, Ranka J & McColl M. (2023). Spirituality in Australian Health Professional Practice: A Scoping Review and Qualitative Synthesis of Findings. *Journal of Religion & Health*, 62(4), 2297–2322. https://doi.org/10.1007/s10943-023-01840-5.
- Spence D. (2017). Supervising for Robust Hermeneutic Phenomenology: Reflexive Engagement Within Horizons of Understanding. *Qualitative Health Research*, 27(6), 836–842. https://doi.org/10.1177/1049732316637824.
- Squires A & Dorsen C. (2018). Qualitative Research in Nursing and Health Professions Regulation. *Journal of Nursing Regulation*, 9(3), 15–26. https://doi.org/10.1016/S2155-8256(18)30150-9.
- Statista (2021). Population of Finland in 2021, by religious community. https://www.statista.com/statistics/532958/population-by-religious-community-in-finland/#professional. Referred to 21.4.2022.
- STM (Sosiaali- ja terveysministeriö). (2020). Kansallinen ikäöhjelma vuoteen 2030: Tavoitteena ikäkyvykäs Suomi. Sosiaali- ja terveysministeriön julkaisuja 2020:31.

- STM (Sosiaali- ja Terveysministeriö). (2020). Laatusuositus hyvän ikääntymisen turvaamiseksi ja palvelujen parantamiseksi 2020–2023 : Tavoitteena ikäystävällinen Suomi. Sosiaali- ja terveysministeriön julkaisuja 2020:29.
- Stoddard G. (1993). Chaplaincy by referral: An effective model for evaluating staffing needs. *Caregiver Journal*, 10(1), 37-52.
- Svenaeus F. (2011). Illness as unhomelike being-in-the-world: Heidegger and the phenomenology of medicine. *Medicine, Health Care & Philosophy*, 14(3), 333–343. https://doi.org/10.1007/s11019-010-9301-0.
- Swanson R. & Chermack T. (2013). *Theory building in applied disciplines* (1st ed.). San Francisco: Berrett-Koehler Publishers.
- Tanyi R. (2002). Towards clarification of the meaning of spirituality. *Journal of Advanced Nursing*, 39(5), 500–509.
- Tavares A, Martins H, Pinto S, Caldeira S, Pontífice Sousa P & Rodgers B. (2022). Spiritual comfort, spiritual support, and spiritual care: A simultaneous concept analysis. *Nursing Forum*, *57*(6), 1559–1566. https://doi.org/10.1111/nuf.12845.
- Taylor A, Armitage S & Kausar A. (2021). A challenge in qualitative research: Family members sitting in on interviews about sensitive subjects. *Health Expectations*, 24(4), 1545–1546. https://doi.org/10.1111/hex.13263.
- Taylor E. (2023). The myth of spirituality. *Journal of Social Work*, 23(6), 1005–1021. https://doi-org.ezproxy.utu.fi/10.1177/14680173231166830.
- Teixeira de Menezes A & Boechat W. (2022). Perspectivism and shamanism in the Jungian clinic: the jaguar as an archetypal image of the Latin American cultural unconscious. *Journal of Analytical Psychology*, 67(1), 317–330. https://doi-org.ezproxy.utu.fi/10.1111/1468-5922.12763.
- Thompson J. ed. (1981). Paul Ricoeur Hermeneutics & the Human Sciences. Essays on language, action and interpretation. Cambridge University Press, USA.
- Thompson J. (1990). Hermeneutic Inquiry. In book: Moody, L. (ed.) 1990. *Advancing Nursing Science Through Research*. Sage Publications, USA. Pages 223-280.
- Toivonen K, Charalambous A & Suhonen R. (2018). Supporting the spirituality of older people living with dementia in nursing care A hermeneutic phenomenological inquiry into nurses" experiences. *Scandinavian Journal of Caring Sciences*, 32(2), 880-888.
- Tuohy D, Cooney A, Dowling M, Murphy K & Sixsmith J. (2013). An overview of interpretive phenomenology as a research methodology. *Nurse Researcher*, 20(6), 17–20.
- Traianou A. (2020). 'The Centrality of Ethics in Qualitative Practice', in Patricia Leavy (ed.), *The Oxford Handbook of Qualitative Research*, 2nd edn, Oxford Handbooks, online edn, Oxford Academic. https://doi.org/10.1093/oxfordhb/9780190847388.013.12, accessed 16 Aug. 2023.
- Trevitt C & MacKinlay E. (2004). 'Just because I can't remember...' Religiousness in older people with dementia. *Journal of Religion, Spirituality and Aging*, 16, 109–121.
- Trivedi S, Subramanyam A, Kamath R & Pinto C. (2016). Study of Spirituality in Elderly With Subjective Memory Complaints. *Journal of Geriatric Psychiatry and Neurology*, 29(1), 38–46. https://doi.org/10.1177/0891988715598235.
- Van Manen M. (1990). Researching lived experience: human science for an action sensitive pedagogy. Albany, N.Y: State University of New York Press.
- Vernooij-Dasssen M, Faber M, Olde Rikkert M, Koopmans R, van Achterberg T, Braat D, Raas G & Wollersheim H. (2009). Dementia care and labour market: the role of job satisfaction. *Aging & Mental Health*, *13*(3), 383–390. https://doi-org.ezproxy.utu.fi/10.1080/13607860902861043.
- Vieten C & Lukoff D. (2022). Spiritual and religious competencies in psychology. *American Psychologist*, 77(1), 26–38. https://doi-org.ezproxy.utu.fi/10.1037/amp0000821.
- Viftrup D, Rosenbæk F, Damgaard H, Hemdrup M, Nielsen M & Nissen R. (2023). Caring Spiritually: A Study on Spiritual Care Training in a Hospice Setting. *Journal of Hospice & Palliative Nursing*, 25(3), 156–164. https://doi-org.ezproxy.utu.fi/10.1097/NJH.0000000000000947.

- Vitorino L, Low G & Lucchetti G. (2019). Is the Physical Environment Associated with Spiritual and Religious Coping in Older Age? Evidence from Brazil. *Journal of Religion & Health*, 58(5), 1648–1660. https://doi-org.ezproxy.utu.fi/10.1007/s10943-019-00796-9.
- Wang W, Yang J, Bai D, Lu X, Gong X, Cai M, Hou C & Gao J. (2024). Nurses' perceptions and competencies about spirituality and spiritual care: A systematic review and meta-analysis. *Nurse Education Today*, *132*, N.PAG. https://doi-org.ezproxy.utu.fi/10.1016/j.nedt.2023.106006.
- Watson J. (2019). Unitary Caring Science Universals of Human Caring and Global Micro practices of Caritas. *NSC Nursing*, 4(1), 1–7. https://doi.org/10.32549/OPI-NSC-22.
- Weathers E, McCarthy G & Coffey A. (2016). Concept Analysis of Spirituality: An Evolutionary Approach. *Nursing Forum*, 51(2): 79-96.
- Widerquist J & Davidhizar R. (1994). The ministry of nursing. *Journal of Advanced Nursing (Wiley-Blackwell)*, 19(4), 647–652. https://doi-org.ezproxy.utu.fi/10.1111/j.1365-2648.1994.tb01134.x.
- Wiklund L, Lindholm L & Lindström U. (2002). Hermeneutics and narration: a way to deal with qualitative data. *Nursing Inquiry*, 9(2), 114–125. https://doi-org.ezproxy.utu.fi/10.1046/j.1440-1800.2002.00132.x.
- Wiles R. (2013). Introduction. In What are Qualitative Research Ethics? London: Bloomsbury Academic. Retrieved December 29, 2023, from http://dx.doi.org/10.5040/9781849666558.ch-001.
- World Health Organization WHO. (2017). Global action plan on the public health response to dementia 2017–2025. Geneva. Licence: CC BY-NC-SA 3.0 IGO.
- World Health Organization WHO. (2021). Ageing and health. https://www.who.int/news-room/fact-sheets/detail/ageing-and-health
- World Medical Association. (2013). WMA Declaration of Helsinki ethical principles for medical research involving human subjects. https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/ Referred to 19.5.2023.
- Wu L & Koo M. (2016). Randomized controlled trial of a six-week spiritual reminiscence intervention on hope, life satisfaction, and spiritual well-being in elderly with mild and moderate dementia. *International Journal of Geriatric Psychiatry*, 31(2), 120–127.
- Wu S, Huang H, Chiu Y, Tang L, Yang P, Hsu J, Liu C, Wang W & Shyu Y. (2019). Dementia-friendly community indicators from the perspectives of people living with dementia and dementia-family caregivers. *Journal of Advanced Nursing*, 75(11), 2878–2889. https://doiorg.ezproxy.utu.fi/10.1111/jan.14123.
- Yeşilçınar İ, Acavut G, İyigün E & Taştan S. (2018). Eight-Step Concept Analysis: Spirituality in Nursing. *International Journal for Human Caring*, 22(2), 34–42.





ISBN 978-951-29-9901-9 (PRINT) ISBN 978-951-29-9902-6 (PDF) ISSN 0355-9483 (Print) ISSN 2343-3213 (Online)