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RESEARCH ARTICLE

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Family members' experiences with the spiritual care of older people living with dementia in nursing homes: A phenomenological hermeneutical study

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Abstract

Aim: To illuminate family members experiences with the spiritual care provided to their family members living with dementia in nursing homes.

Design: A qualitative research design utilizing phenomenological hermeneutical approach.

Methods: Data were gathered by conducting twelve in-depth interviews with family members of older people living with dementia in nursing homes and analysed using the phenomenological hermeneutical analysis. The COREQ guidance was used for reporting of this study.

Results: Finding revealed that family members were worried and fearful when nursing care was routinely provided with little consideration given to spiritual needs and lacking compassion. Findings affirm that "riendliness" is an essential aspect of respectful caring from the family members' perspective. Family members want compassionate, loving, caring and dignified nursing care for their relative living with dementia in the nursing homes.

KEYWORDS

dementia, family members, nursing homes, older people, spiritual care

1 | INTRODUCTION

When a family member (FM) cannot take care of an older person with dementia, they may seek accommodation in a nursing home, where their relative can receive appropriate and safe nursing care. The most common reasons for seeking nursing home accommodation for older people living with dementia are family caregivers' distress, burden and even depression. Family members can feel both a sense of relief and concern for their relative after placement in a nursing home. Family members expect that their older FM living with dementia will receive good-quality holistic nursing care. Care that will meet not only their physical needs but incorporating their spiritual needs will be truly holistic.

2 | BACKGROUND

Spirituality, as a universal concept, is very personal and deeply individual (McSherry & Smith, 2012). The European Association for Palliative Care (EAPC) defines spirituality as "The dynamic dimension of human life that relates to the way person experience, express

and/or seek meaning, purpose, and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred" (Nolan et al., 2011). This definition affirms spirituality is something unique, at the core and essence of a person, permeating the entire structure of their life. It applies to people who may have a religious belief and those who do not. Spirituality is crucial for good health (Büssing & Koenig, 2010; Vincensi & Burkhart, 2016) as it is strongly associated with well-being (Visser et al., 2010) and higher quality of life (Labrague et al., 2016). Spiritual well-being is essential for a wider understanding of the concept of health (Chirico, 2016) and is crucial in an occupational setting (Chirico & Magnavita, 2019). It may also be a useful coping mechanism, especially for certain professions (Chirico et al., 2020), including healthcare professionals (Chirico & Nucera, 2020).

Spiritual care is defined as care, which "recognizes and responds to the needs of the person's spirit when faced with life-changing events and include the need for meaning, for self-worth, to express oneself, for faith support, for sacred rites or just for a sensitive listener" (Enhancing Nurses' and Midwives' Competence in Providing Spiritual Care through Innovative Education and Compassionate Care (EPICC). (2019)). Older people with dementia can reflect expressions of different spiritual needs as dissatisfaction due to physical discomfort, emotional distress and social isolation (McSherry et al., 2016). The spiritual needs of older people living with dementia can be understood through verbal and nonverbal expressions and by valuing their spiritual backgrounds (Toivonen et al., 2018). Spiritual needs are intimately related to human dignity, deep listening and understanding the older person's whole story, including the things that matter most in their lives (Puchalski, 2015). The spiritual needs, besides the sense of meaning, also include the need for expressing self-worth (Toivonen et al., 2015) and correspond with existential, emotional, social and religious categories (Erichsen & Büssing, 2013). Mitty (2010) states that when spiritual needs are met, the effects of stressful events are indirectly reduced, including fear of the unknown and death. Spirituality can reduce the feelings of loneliness among older people living with dementia (Ceramidas, 2012). This can lead to an increase in their quality of life and well-being (Keast et al., 2010) by reducing stress and depression (Puchalski, 2015), which in turn may be associated with lower morbidity and mortality rates (Oman, 2018).

Older people often use spiritual beliefs to cope with the losses and changes in their lives, especially around decreasing independence and cognitive impairment (Peteet et al., 2018). Therefore, spiritual care for people living with dementia is essential, primarily from a personal and ethical perspective and a health perspective, since it enables individuals to cope and live with the disease (Agli et al., 2015). It is also fundamental from the perspective of assessing spiritual needs and ensuring the appropriate care is provided (Dewing, 2008; Powers & Watson, 2011).

The evidence presented would support addressing the spiritual needs, and providing spiritually competent nursing care for people living with dementia in a nursing home is essential. Walmsley and McCormack (2016) stressed the importance of a person-centred approach in addressing and providing spiritual care, which should always be within the context of a compassionate relationship (Timmins & McSherry, 2012; Weathers et al., 2016). There is evidence of the importance of integrating spirituality within the nursing care of older people living with dementia in nursing homes (Goodall, 2009; Keast et al., 2010; Ødbehr et al., 2014, 2015, 2017; Powers & Watson, 2011; Toivonen et al., 2018). This is fundamental to ensure the quality of life and dignity (Beuscher & Grando, 2009; Daly & Fahey-McCarthy, 2014; Goodall, 2009) of older people living with dementia are upheld. Therefore, nursing staff must understand the importance of spirituality in a person's life (van Leeuwen & Schep-Akkerman, 2015; McSherry, 2006; McSherry & Jamieson, 2011). If nursing staff understand and integrate the concept of spirituality within their care, this will ensure a person-centred approach and humanizing nursing care (NHS Education for Scotland, 2009). Person-centred care is described as an individual and holistic approach that focuses on the person's needs and desires (McCormack & McCance, 2016). Such an approach enables the person to take an active role in their treatment by making clear decisions and expressing their real wishes (McCormack & McCance, 2016). A person-centred care philosophy refers to personal values that differ according to cultural differences, politics, spirituality, and personal view of life and emphasizing personhood (Broom, 2020; McCormack & McCance, 2016). The philosophy of person-centred care affirms that these two concepts have a synergistic and symbiotic relationship. For example, you cannot provide person-centred care if you fail to address the person's spiritual dimension. Therefore, person-centred principles are essential for ensuring older people's spiritual needs.

Family Members can feel anger, disappointment and even guilt because of having to place a loved one living with dementia in a nursing home (Graneheim et al., 2014; Lord et al., 2016; Seiger Cronfalk et al., 2017). The FMs expectations of good nursing care of their older FM living with dementia in the nursing home are very high (Fekonja et al., 2021). Family member expect the nursing staff to provide holistic practice incorporating spiritual care for their FM living with dementia.

In summary, the importance of spiritual care for older people is acknowledged in the research and opinion literature. Also evident is a gap in the literature that spiritual care for older people living with dementia is under-researched. Ødbehr et al. (2017) recommended further research about spirituality in people living with dementia in nursing homes, especially from the FM perspective. Therefore, this study focused on FMs' experiences with the spiritual care of their relatives living with dementia in nursing homes, thereby offering new insights into this neglected field of clinical practice.

The purpose of this study was to find a deeper understanding of the experience of receiving spiritual care while living with dementia in a nursing home from the perspective of FMs.

3 | METHOD

3.1 | Study design

A qualitative methodology design based on Heidegger's philosophy of truth in lived experiences (Heidegger, 1946/2008, p. 2018) was

chosen in this study. The phenomenological hermeneutical method was used (Lindseth & Norberg, 2004). The phenomenological hermeneutical method is suitable for illuminating lived experience from interviews (Lindseth & Norberg, 2004) and has been widely used to explore spirituality (Henricson et al., 2009; Toivonen et al., 2015, 2018). The method enables a researcher to focus on the apparent meaning of the experience (Lindseth & Norberg, 2004), which was the spiritual care given to older people living with dementia in a nursing home from the FM's perspective. Consolidated Criteria for Reporting Qualitative research (COREQ) (Tong et al., 2007) was used as a guide for reporting this study (see Supplementary File 1).

3.2 | Participants

Purposive sampling (Polit & Beck, 2012) of the FMs of older people living with dementia was used. Participants recruited were FMs who had an older relative diagnosed with dementia living in a large nursing home in the Styria region in Slovenia. The nursing home comprises four 200-bed units. The head nurse of each unit conducted the recruitment according to the following inclusion criteria: a FM of older people (65 + years) diagnosed with dementia, living in the nursing home at least 6 months; the FM is a child or spouse or unmarried partner who does not live in the nursing home; and he or she has not been diagnosed with dementia or other cognitive or psychiatric condition and can sign the consent form voluntarily. Thirty ($n = 30$) FMs agreed to be further contacted. The first author subsequently contacted all of them to give more information about the study's aim and rationale. Participants from the 30 who had taken up the invitation were randomly selected to participate in the study.

3.3 | Data collection

Data were collected between August and October 2019 using in-depth face-to-face individual interviews to fulfil the study's purpose. The first author arranged a convenient date and time with each participant. All interviews were conducted in a nursing home. No one else was present besides the participant and the researcher. Each participant was interviewed once. The interviews lasted between 92 and 109 min (average 96 min) using an interview guide that conformed to phenomenological methodology and was pilot tested before use in this study.

The 12 participants were asked open-ended questions: for example, "What are your experiences with the spiritual care of your relative who is living with dementia in the nursing home?" During the interview, the interviewer asked the participants to clarify and examples by encouraging with exploratory questions such as "Can you tell me a bit more, please…" and "Can you give me an example, please…" When conducting interviews, the participants were encouraged to narrate, as freely as possible, their lived experience of spiritual care. The tone of speech, mood, nonverbal behaviours and participants' expressed feelings were documented and served as data analysis. Field notes were also used (Finlay, 2014), helping the researcher delves more in-depth into spiritual care experiences. Data collection ended after 12 in-depth interviews, at which point when the data saturation was reached and no new themes were identified to illuminate the phenomenon (Polit & Beck, 2012). The first author conducted all the interviews using the techniques outlined to enable participants to talk freely about their experiences with the spiritual care of their FM living with dementia in the nursing home. The first author (interviewer) has considerable clinical experience in the nursing care of older people living with dementia. She has experience conducting in-depth interviews as part of other research projects. All the interviews were audio-recorded and transcribed verbatim and were not returned for member checking.

3.4 | Data analysis

The hermeneutical phenomenological design was used to provide a new, fruitful way of understanding and to gain in-depth insight into the thoughts, emotions, feelings and activities (Lindseth & Norberg, 2004) of the phenomena of spiritual care as experienced by older people living with dementia in a nursing home through the lens of FMs.

Firstly, the audio-recorded interviews were listened to many times. Then, each interview was transcribed verbatim with pauses marked by empty intervals in the text. The transcribed text was compared with the audio-recording and adjusted where necessary. The text was also read many times to obtain a sense of the whole and initially comprehend the spiritual care of older people living with dementia in nursing homes. Naïve reading, named by Lindseth and Norberg (2004), guides the interpretation process in the second step, where the authors move back and forth through the text to find meaning. The text was divided into meaning units and condensed according to similarities. Then, the subthemes and themes (Table 1) were created through the dialectic process of parts and wholeness (Lindseth & Norberg, 2004). For example, in this phase, the authors continually engage with individual participants' transcripts and mapped differences and similarities across all the transcripts to further develop subthemes and themes. At the third step, the naïve reading of subthemes, themes and understanding was reflected upon and interpreted without the authors bracketing their pre-understanding (Finlay, 2014) of spiritual care in older people living with dementia in nursing homes. The authors were very conscious of how professional and personal experiences, beliefs, values and attitudes towards spirituality could potentially influence and bias the analysis and findings. Therefore, the importance of reflexivity was central to ensuring this did not occur. This was achieved by reflecting upon these issues, both individually and as a team, by making sure that these were declared and discussed. Because of the nature of phenomenology, it was not possible to bracket or remove this rich experience; instead, it contributed to the comprehensive understanding of the delivery of spiritual care. The first four authors'

TABLE 1 Overview of themes and subthemes

Themes	Subthemes
Being in distress	Unmet spiritual needs
	Routinely performed care
	Enduring insecurity
Expecting respectful care	Spending time and listen carefully
	Expecting loving care
	Expecting to provide dignified care
	Expecting to obtain life histories
Expecting compassionate care	A sense for sensitive care
	Expecting compassion, understanding and thoughtfulness
	Expecting a sense of caring
	Not being focused on little things
	Not being focused on essential things

professional work as registered nurses with older people also contributed to the comprehensive understanding.

The software qualitative analytical program MAXQDA was used for organizing the meaning units. All themes were summarized and reflected upon and considered against the main purpose of the study. All the texts were re-read with the naïve associations, and relevant literature was sourced and reviewed to widen and deepen the text's understanding (Lindseth & Norberg, 2004). In creating subthemes and themes, we ensured that the themes ran through the meaning units. Credibility was addressed by revisiting and listening to the audio-recorded interviews. Three authors (NMR, SK, ZF) independently coded the data. Participants were not involved in the final analysis and interpretation process. The data analytical process was reviewed and approved by the leading author. A discussion between all authors strengthened validity. The research process was audit trailed, reported and recorded to ensure confirmability and dependability (Polit & Beck, 2012).

3.5 | Ethical considerations

The study was approved by the National Medical Ethics Committee (No: 0120-459/2017/4). The ethical considerations related to the FMs of older people with dementia ensured confidentiality, voluntary participation and informed consent. Pseudonyms are employed to preserve participant anonymity.

4 | RESULTS

Participants were aged between 48 and 70 years; seven were females, and five were males. The participants' mean age was 55 years. Five of the participants were sons, and six were daughters; one was the wife of one of the nursing home residents. Seven participants were married, three participants lived in a non-marital partnership, one was a widower, and one was divorced. Seven of them had completed high school and held a higher degree; two had a master's degree; and three had finished secondary school. All except one participant who was retired were employed. All of them made regular visits to their FM at least twice a week. Their FMs had lived in the nursing home between 11 months and three and a half years as present in Table 2.

4.1 | Naïve understanding

Each interview was listened to and read several times to gain an impression of the whole. The reading showed that FMs were worried about their relatives' spiritual care while living with dementia in a nursing home. The fear that spiritual needs were not met was sensed and evident. Family members described that bad mood, distress and incomprehension were expressed because of the lack of spiritual care or unsatisfactory addressing of the spiritual needs of their relative living with dementia. Family member suggested that older people with dementia preferred those nursing staff who quickly recognized their spiritual needs and responded appropriately.

Similarly, FMs stressed the importance of rapid adaptation to current spiritual needs and situations in which the older persons with dementia found themselves. That is why FMs wanted compassionate, loving, caring and dignified nursing care, which they expected. They also wanted nursing staff to be competent concerning these areas of care. Interestingly, FMs reported that their relatives living with dementia had not changed profoundly in themselves and still the same person. Word clouds present the most common words used to express FMs' experiences with the spiritual care of older people living with dementia in nursing homes (see Figure 1).

4.2 | Structural analysis

Family members experiences with the spiritual care of older people living with dementia in nursing homes are illustrated by the main themes "Being in distress," "Expecting respectful care" and "Expecting compassionate care" that emerged through the structural analysis.

TABLE 2 Demographic characteristics of the participants

Participant pseudonym	Participant gender/age (years)/ marital status	Religion	Profession / occupation	Relationship with an older person living with dementia/ age (years)	Length of living in a nursing home (months)
Andrew	M / 59 / married	Roman Catholic	Computer engineer / self employed	father / 82	11
Betty	F / 48 / married	Roman Catholic	Secretary / employed	mother / 70	18
Camilla	F / 56 / married	Roman Catholic	Teacher / employed	mother / 78	28
Donna	F / 70 / married	Roman Catholic	Accountant / retired	husband / 73	26
Emanuele	F / 52 / married	Atheist	Lawyer / employed	mother / 74	21
Frank	M / 57 / married	Roman Catholic	Economist / employed	mother / 86	30
Gregory	M / 56 / widow	Orthodox catholic	Salesman / employed	mother / 81	13
Hanna	F / 51 / divorced	Atheist	Nurse / employed	father / 72	42
Ivanna	F / 49 / unmarried partnership	Roman Catholic	Hairdresser / self employed	father / 71	14
John	M / 59/ married	Roman Catholic	Mechanical engineer / employed	mother / 84	22
Karin	F / 49 / unmarried partnership	Roman Catholic	Housekeeper / unemployed	father / 70	12
Larson	M / 57 / unmarried partnership	Atheist	Policeman—detective / retired	mother / 85	16

Abbreviations: F, female; M, male.

FIGURE 1 Frequently used words in expressing family members (FMs) experiences with spiritual care

4.2.1 | Being in distress

Family members experienced many unmet spiritual needs, and they felt that nursing care was routinely provided with a lack of spiritual and compassionate care. Also, enduring insecurity was mostly expressed. Family members were worried about their relative, especially when their spiritual needs were not recognized and satisfactorily met. Lack of spiritual care was often expressed as a lack of person-centred care.

> *Mom has a colleague in the first floor and goes to chat with her. Sometimes she takes her photo album with her, and they look at the pictures… This makes her happy and smiley … But she needs somebody to take her downstairs, not to go alone (she gets lost). This makes her happy. This is perhaps irrelevant for the staff, but she is in a good mood the whole day. She needs fewer painkillers and sleeps without a pill. She is so satisfied with them. (Betty)*

The routine nursing care that is not person-centred was commonly expressed as stressful for FMs. Some of them expressed that nursing care is not personalized and person-centred but provided through a daily routine.

> *They have their schedule … when they put them in bed, when changing their pads, when they are bathing them… Nothing is adapted to Mom, what and when she wants it. She always had a shower in the evening, but here they bathe her after breakfast. This makes Mom nervous because she does not like it, and they say that she is nagging. Of course, she does, because her wishes and needs are not taken into account. (Camilla)*

> *Everything is predetermined… waking up, hygiene, breakfast, board games, lunch, … It doesn't matter if my husband wants it or not. He has to! … (Donna)*

Unmet spiritual needs in older people living with dementia were shown in nurses' inability to recognize and/or respond to spiritual

needs. The need to be understood and to be worthy are such commonly unmet spiritual needs in older people living with dementia expressed by FMs. The situations with unmet spiritual needs led FMs to experience a state of constant insecurity, wondering in what situation their loved one will be at the next visit. Such situations are also very stressful for them. Hanna described feelings as being in an impossible situation:

> *Nobody here understands him. It hurts me, … (pause). I do not know how this will go on because he is so demented. I feel that the world has collapsed, and now I do not know how and what I can do. I do not have any solutions, and I do not even know where to look for any because there is no solution here (holding back tears). (Hanna)*

4.2.2 | Expecting respectful care

Family members wanted respectful care to be provided. This theme was derived from the subthemes: Spending time and listen carefully; Expecting loving care; Expecting to provide dignified care; and Expecting to obtain life histories. Through attentive listening, understanding and focusing on the older person when talking, nurses respected the older person living with dementia. Emanuele reported:

> *… but she needs so little to be happy… a smile, a touch, to sit down a moment, to look her in the eye and let her know that they understand her, to listen to her, although what she says is not related and slow and in the meantime changed to other things.*

Friendliness is an essential aspect of caring for older people with dementia from the FMs' perspective. Friendly caring is fundamental, as observed:

> *She is limited because her functions are no longer working in the same way as before. That is why I want nurses to treat her as a person who has become ill. And not as a half-witted thing who does not speak, not understand… I want the staff to be kind to her, although she sometimes does things wrongly. (John)*

Family members wanted not only friendly and caring staff but also dignified nursing care. Many participants highlighted that dignity should be expressed because older people living with dementia are *"still the same person as before dementia set in" (Frank)*. Respecting dignity is also reflected in the activities of daily living, like toileting or bathing, as expressed below:

> *My dad does not like to bathe. Before he became ill, he had a shower every day. Now? No way! Sometimes, when a nurse forces him to bath in the bathroom, he becomes aggressive and screams. The staff could try a different way with him. I gently take him by the hand, take fresh clothes, go to the bathroom, and first let him put his hands in the water to feel it. And I always play his favorite music. He sings and dances under the shower (smile). No protests. Nevertheless, not to take him with force… (he stops, cries…) Is this spirituality? (Karin)*

The FMs expressed that the nursing staff respected their relatives' religious dimensions of spirituality. The staff freely talked about religious themes, such as helping residents maintain their spiritual practices by facilitating their spiritual communities. Respect for older people living with dementia in the nursing home and their relatives is also shown by obtaining and knowing the person's life history. The FMs expressed concern about the high turnover of nursing staff in the nursing home. Hence, the staff did not know either the family's values or the older people's life histories. One relative explained the importance of life history and how this contributed to the quality of care:

> *Well, they do not know the residents. The staff change too often… They do not know much about Mom, except that she has a son, me. I come with family, her grandchildren. They could know Mom's history a little bit in order to understand her better. These are things that intertwine. It would be easier for staff and these people if they knew something about them, what they did in life, what difficulties experienced in life, what they liked, and what stimulated them. (Larson)*

4.2.3 | Expecting compassionate care

This theme incorporated the subthemes: a sense for sensitive care, expecting compassion, understanding and thoughtfulness, expecting a sense of caring, not being focused on little things and not being focused on essential things. Family members reported differences in providing nursing care for older people living with dementia. They highlighted that some nursing staff could better recognize a person's mood and adjust the required nursing care more adequately. Family members expected from the nursing staff a sensitivity providing appropriate person-centred care for their relative, as expressed by Andrew:

> *Sometimes the staff tell that he is having a stressful day and that he is not in a good mood. The nurses see this. Then they do not force him to do anything. They let him go, and he does not have to. They judge it well. Well, they know better than others. Sometimes, when a nurse forces him, everything gets worse. Two nurses are kind and gentle because they can deal well with him and do not force him. For example, if he does not want to eat lunch, they give him dessert instead because he loves cookies. Never mind if he first eats the pudding and then the soup.*

People living with dementia often do not understand what is going on, but they still can sense and know what is happening. Therefore, excellent nursing care is the one thing the FMs expect from the staff. One participant expressed her feelings:

> *It seems that he feels all this is happening around him rather than perceiving it by reasoning. He is still aware, so the staff must also nurse him with sensitivity, gentleness, lovingly, and not too fast and so insensitive. This hurts. (Ivanna)*

Some FMs express dissatisfaction when nurses do not care for important things for people living with dementia. Frank reported such an experience:

> *My mum is used to drinking green tea every afternoon. I know it has been her ritual from the times she was working. I told this to the staff. I beg the nurse if they can prepare her a green tea. But it happened very rarely. I can't understand why this could be a problem. They know how much it means for her.*

Nurses should be focused upon and pay attention to the little but essential things, as these contribute significantly to compassionate nursing care:

> *Well, coffee with sugar should be obligatory. It works miracles. If there is a cake, then happiness is assured. We go with to the cafeteria here. That is her food for the soul, she says. It is true. Then she is suddenly cheerful and smiling. Nothing hurts her, although she sits in the wheelchair for two hours. (Gregory)*

4.3 | Comprehensive understanding

Keeping in mind the purpose of the study, the naïve reading, structural analysis, and our preconceptions and understandings, a comprehensive understanding of the whole emerged. The study illuminated FMs' experiences of the spiritual care provided to older people living with dementia in the nursing home. Family members had their spiritual care expectations, which influenced their understanding of how nursing care should be given to their relative living with dementia. Also, the FM's previous experiences and personal expectations determine their assessment of the quality of nursing care provided. Family members clearly expressed their wishes and expectations for the best care possible in the nursing home. Therefore, we understand the distress and expectations for respectful and compassionate care of their relative. It seems that unfulfilled expectations can impair their notions of compassionate care for their relatives. Compassionate care was considered the main priority when caring for older people living with dementia from the perspective of FMs. The FM's expectations of respectful caring of people living with dementia are entirely justified. In addition to a respectful relationship, FMs also expected a friendly, cheerful, sincere and loving nursing care, where nurses do their best for the residents, taking care of them in a loving way, with a great deal of compassion.

5 | DISCUSSION

This study's focus was to acquire a deeper understanding of how spiritual care was experienced by older people living with dementia in a nursing home from the perspective of their FMs. In the interviews, the participants expressed that their relatives' spiritual needs were often not addressed, remained unmet and often neglected. This situation caused considerable distress and anxiety for some FMs. These findings are consistent with Peteet et al. (2018), who found that not addressing or failing to address spiritual needs led to lower quality of life and reduced satisfaction with the nursing care given. Toivonen et al. (2018) note that nurses should be able to assess spiritual needs. While this study found that there are variations, some nurses can do this much better than others.

It should be noted that spiritual needs in people with dementia can quickly change and are expressed differently. Therefore, the nursing staff must be competent to make rapid and sudden adjustments to their care plan (Austin et al., 2017). The problem can be that nursing staff cannot recognize and meet spiritual needs, as found in our study. Spiritual care recognizes and responds to the needs of the person's spirit when faced with life-changing events and includes the need for meaning, self-worth, express oneself, faith support, sacred rites or just for a sensitive listener (EPICC, 2019). Spiritual care begins with a compassionate relationship (NHS Education for Scotland, 2009) and should always be person-centred (Koenig, 2013; Walmsley & McCormack, 2016).

Moreover, spiritual care cannot be adequately and effectively provided without a person-centred approach (NHS Education for Scotland, 2009). According to Lewinson et al. (2018), respect, dignity and connectedness represent fundamental spiritual care. Our findings highlighted that respect, dignity and compassion were expected when caring for older people with dementia.

Nurses are responsible for delivering spiritual care in its broadest sense with respecting the individual's dignity, humanity, individuality and diversity (NHS Education for Scotland, 2009). Walmsley and McCormack (2016) state that nursing home staff must consider the values, individualism and the social component of people with dementia. Our findings show that daily activities are not person-centred, but often routine and mechanistic undertaken even if the residents want them or not. Daily nursing activities are not planned or based on older people's individual needs. The nursing activities in nursing homes were organized according to time and rituals. Austin et al. (2017) suggest that it is necessary to recognize the essential things and not impose the nurses' beliefs upon people. Providing routine care can be a sign of a lack of compassion and sympathy. Our findings show that FMs expect a respectful attitude to older people with dementia. Dewing (2008) highlighted that every person has an absolute value and that every person should be

embedded within a social group that provides integrity, continuity and stability. Friendly and cheerful caring, respecting privacy and dignity, should be provided by nursing staff (Timmins et al., 2014) in all nursing homes. Thus, nursing care for people living with dementia must be compassionate and respectful. Compassion is displayed and given when a nurse empathizes with vulnerable people providing nursing care that is relevant and appropriate for older people (Kagan, 2014). Spirituality is embedded in nursing practice core values, such as caring, compassion and dignity (Timmins & McSherry, 2012). Providing spiritual care to promote and ensure inner peace is necessary as it has a positive impact on the behavioural and psychological symptoms of people with dementia (McSherry et al., 2016). Spiritual care begins by establishing an authentic interpersonal contact between nurses and people living with dementia, which is a foundation for compassionate nursing. Having a loved one living with dementia in a nursing home cause feelings of moral concern in FMs (Seiger Cronfalk et al., 2017). Nurses in nursing homes should offer support to the FMs to understand the care of their loved ones living with dementia (Cabote et al., 2015). Communication is key to mutual respect and offering person-centred care to the people living with dementia in the nursing homes and their FMs.

5.1 | Limitations

A limitation of this study is the sample of participants. We cannot generalize the findings from this study. It is necessary to consider that only one interview with each participant was carried out. Repeated interviews would have increased the trustworthiness. The authors help the reader judge the study findings' trustworthiness by using the participants' quotes.

The study was carried only in one nursing home. It would be interesting to repeat the study in a range of nursing homes that have been judged as delivering excellent care and those who require improvement. As a limitation, we should also mention the language differences, as the results were translated into English.

The lead author did not disregard their presuppositions during interviews but sought to have a reflective attitude when discussing the findings in which all the authors let their pre-understanding be challenged and opened up for new ideas.

The sample in this study consisted of various FMs in terms of gender, age and relationship, and different cultural and religious backgrounds. This enriches the data set, which is a prerequisite for rigour in qualitative research (Tong et al., 2007). However, the sample was selected on the voluntary participation of FMs who were willing to share their experiences. Family members who participate in this study may have had different experiences from those who did not want to participate.

6 | CONCLUSION

Findings from the study show that FMs were worried and fearful when nursing care was routinely provided with a lack of spiritual and compassionate care. The friendliness of the nursing staff was a crucial part of respectful caring from the FMs' perspective. Family members wanted compassionate, loving, caring and dignified nursing care for their relative.

The study revealed a need to develop a model of spiritual care for people living with dementia in nursing homes. There is also a need to research the nursing staff's perspective of spiritual care and also to research the perspective of people living with dementia to gain a more holistic insight into the nursing practice of spiritual care in nursing homes.

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CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

AUTHOR CONTRIBUTIONS

NMR, BKP and MP contributed in conception and design of the study. NMR, SK and ZF contributed in data analysis and synthesis. NMR and WM contributing in background and discussion section and in drafting the manuscript. NMR, ZF, SK, WM, BKP and MP approval the manuscript version to be published.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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REFERENCES

Agli, O., Bailly, N., & Ferrand, C. (2015). Spirituality and religion in older adults with dementia: A systematic review. *International Psychogeriatrics*, *27*(5), 715–725. https://doi.org/10.1017/S1041610214001665

Austin, P., Macleod, R., Siddall, P., McSherry, W., & Egan, R. (2017). Spiritual care training is needed for clinical and non-clinical staff to manage patients' spiritual needs. *Journal for the Study of Spirituality*, *7*(1), 50–63. https://doi.org/10.1080/20440243.2017.1290031

Beuscher, L., & Grando, V. T. (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

Broom, B. (2020). The practice of whole person-centred healthcare. In R. L. Anjum, S. Copeland, & E. Rocca (Eds.), *Rethinking causality, complexity and evidence for the unique patient: A cause health resource for healthcare professionals and the clinical encounter* (pp. 215–226). Springer. https://doi.org/10.1007/978-3-030-41239-5_14

Büssing, A., & Koenig, H. G. (2010). Spiritual needs of patients with chronic diseases. *Religions*, *1*, 18–27. https://doi.org/10.3390/rel1010018

Cabote, C. J., Bramble, M., & McCann, D. (2015). Family caregivers' experiences of caring for a relative with younger onset dementia: a qualitative systematic review. *Journal of Family Nursing*, *21*(3), 443–468. https://doi.org/10.1177/1074840715573870

Ceramidas, D. M. (2012). Faith-based cognitive behavioral therapy: Easing depression in the elderly with cognitive decline. *Journal of Christian*

Nursing: A Quarterly Publication of Nurses Christian Fellowship, *29*(1), 42–48. https://doi.org/10.1097/CNJ.0b013e318238f288

Chirico, F. (2016). Spiritual well-being in the 21st century: It's time to review the current WHO's health definition? *Journal of Health and Social Sciences*, *1*(1), 11–16. http://journalhss.com/wp-content/uploads/JHHS1111-16.pdf

Chirico, F., & Magnavita, N. (2019). The spiritual dimension of health for more spirituality at workplace. *Indian Journal of Occupational and Environmental Medicine*, *23*(2), 99. https://doi.org/10.4103/ijoem.IJOEM

Chirico, F., & Nucera, G. (2020). An Italian experience of spirituality from the coronavirus pandemic. *Journal of Religion and Health*, *59*, 2193–2195. https://doi.org/10.1007/s10943-020-01036-1

Chirico, F., Sharma, M., Zaffina, S., & Magnavita, N. (2020). Spirituality and prayer on teacher stress and burnout in an italian cohort: A pilot, before-after controlled study. *Frontiers in Psychology*, *10*, 1–7. https://doi.org/10.3389/fpsyg.2019.02933

Daly, L., & Fahey-McCarthy, E. (2014). Attending to the spiritual in dementia care nursing. *British Journal of Nursing*, *23*, 787–792. https://doi.org/10.12968/bjon.2014.23.14.787

Dewing, J. (2008). Personhood and dementia: Revisiting Tom Kitwood's ideas. *International Journal of Older People Nursing*, *3*(3), 3–13.

Enhancing Nurses' and Midwives' Competence in Providing Spiritual Care through Innovative Education and Compassionate Care (Epicc). (2019). *Spiritual Care Education Standard*. http://blogs.staffs.ac.uk/epicc/resources/

Erichsen, N. B., & Büssing, A. (2013). Spiritual needs of elderly living in residential/nursing homes. *Evidence-Based Complementary and Alternative Medicine*, *2013*, 1–10. https://doi.org/10.1155/2013/913247

Fekonja, Z., Kmetec, S., Novak, B., McCormack, B., & Mlinar Reljić, N. (2021). A qualitative study of family members experiences of their loved one developing dementia and their subsequent placement in a nursing home. *Journal of Nursing Management*, *29*, 1–9. https://doi.org/10.1111/jonm.13267

Finlay, L. (2014). Engaging phenomenological analysis. *Qualitative Research in Psychology*, *11*(2), 121–141. https://doi.org/10.1080/14780887.2013.807899

Goodall, M. A. (2009). The evaluation of spiritual care in a dementia care setting. *Dementia*, *8*, 167–183. https://doi.org/10.1177/1471301209103249

Graneheim, U. H., Johansson, A., & Lindgren, B. M. (2014). Family caregivers' experiences of relinquishing the care of a person with dementia to a nursing home: Insights from a meta-ethnographic study. *Scandinavian Journal of Caring Sciences*, *28*, 215–224. https://doi.org/10.1111/scs.12046

Heidegger, M. (1946/2008). Letter on humanism. In D. F. Krell (Ed.), *Martin Heidegger, basic writings* (Rev., pp. 213–265). Harper Perennial Modern Classics.

Henricson, M., Segesten, K., Berglund, A. L., & Määttä, S. (2009). Enjoying tactile touch and gaining hope when being cared for in intensive care-A phenomenological hermeneutical study. *Intensive and Critical Care Nursing*, *25*, 323–331. https://doi.org/10.1016/j.iccn.2009.07.001

Kagan, S. H. (2014). Compassion. *Geriatric Nursing*, *35*(1), 69–70. https://doi.org/10.1016/j.gerinurse.2013.11.006

Keast, K., Leskovar, C., & Brohm, R. (2010). A systematic review of spirituality and dementia in LTC. *Annals of Long-Term Care*, *18*, 41–47.

Koenig, H. G. (2013). *Spirituality in patient care* (3rd ed.). Templeton Press.

Labrague, L. J., McEnroe-Petitte, D. M., Achaso, R. H., Cachero, G. S., & Mohammad, M. R. A. (2016). Filipino nurses spirituality and provision of spiritual nursing care. *Clinical Nursing Research*, *25*, 607–625. https://doi.org/10.1177/1054773815590966

Lewinson, L., McSherry, W., & Kevern, P. (2018). "Enablement"—spirituality engagement in pre-registration nurse education and practice: A grounded theory investigation. *Religions*, *9*(11), 356. https://doi.org/10.3390/rel9110356

Lindseth, A., & Norberg, A. (2004). A phenomenological hermeneutic method for researching lived experience. *Scandinavian Journal Caring Sciences*, *18*, 145–153.

Lord, K., Livingston, G., Robertson, S., & Cooper, C. (2016). How people with dementia and their families decide about moving to a care home and support their needs: Development of a decision aid, a qualitative study. *BMC Geriatrics*, *16*(1), 1–8. https://doi.org/10.1186/s12877-016-0242-1

McCormack, B., & McCance, T. (2016). *Person-centred practice in nursing and health care theory and practice* (2nd ed). John Wiley & Sons.

McSherry, W. (2006). The principal components model: A model for advancing spirituality and spiritual care within nursing and health care practice. *Journal of Clinical Nursing*, *15*, 905–917. https://doi.org/10.1111/j.1365-2702.2006.01648.x

McSherry, W., & Jamieson, S. (2011). An online survey of nurses' perceptions of spirituality and spiritual care. *Journal of Clinical Nursing*, *20*, 1757–1767. https://doi.org/10.1111/j.1365-2702.2010.03547.x

McSherry, W., & Smith, J. (2012). Spiritual care. In W. McSherry, R. McSherry, & R. Watson (Eds.), *Care in nursing. Principles, values and skills* (pp. 117–134). Oxford University Press.

McSherry, W., Suckling, S., & Boughey, A. (2016). Searching for life meaning: Spiritual discourses in dementia leadership using interpretative phenomenological analysis. *Journal for the Study of Spirituality*, *6*, 89–105. https://doi.org/10.1080/20440243.2016.1158458

Mitty, E. (2010). Storytelling. *Geriatric Nursing*, *31*, 58–62. https://doi.org/10.1016/j.gerinurse.2009.11.005

NHS Education for Scotland. (2009). *Spiritual care matters. An introductory resource for all NHS Scotland staff*. NHS Education for Scotland. http://www.nes.scot.nhs.uk/media/3723/spiritualcaremattersfinal.pdf

Nolan, S., Saltmarsh, P., & Leget, C. (2011). Spiritual care in palliative care: Working towards an EAPC task force. *European Journal of Palliative Care*, *18*(2), 86–89.

Ødbehr, L. S., Hauge, S., Danbolt, L. J., & Kvigne, K. (2017). Residents' and caregivers' views on spiritual care and their understanding of spiritual needs in persons with dementia: A meta-synthesis. *Dementia*, *16*, 911–929. https://doi.org/10.1177/1471301215625013

Ødbehr, L. S., Kvigne, K., Hauge, S., & Danbolt, L. J. (2014). Nurses' and care workers' experiences of spiritual needs in residents with dementia in nursing homes: A qualitative study. *BMC Nursing*, *13*, 1–9. https://doi.org/10.1186/1472-6955-13-12

Ødbehr, L. S., Kvigne, K., Hauge, S., & Danbolt, L. J. (2015). Spiritual care to persons with dementia in nursing homes; A qualitative study of nurses and care workers experiences. *BMC Nursing*, *14*, 70. https://doi.org/10.1186/s12912-015-0122-6

Oman, D. (2018). Religious/spiritual effects on physical morbidity and mortality. In D. Oman (Ed.), *Why religion and spirituality matter for public health. religion, spirituality and health: a social scientific approach*. Springer. https://doi.org/10.1007/978-3-319-73966-3_4

Peteet, J. R., Zaben, F. A., & Koenig, H. G. (2018). Integrating spirituality into the care of older adults. *International Psychogeriatrics*, *31*, 31–38. https://doi.org/10.1017/s1041610218000716

Polit, F. D., & Beck, C. T. (2012). *Nursing research: generating and assessing evidence for nursing practice* (9th ed.). Wolter Kluwer Health.

Powers, B. A., & Watson, N. M. (2011). Spiritual nurturance and support for nursing home residents with dementia. *Dementia*, *10*, 59–80. https://doi.org/10.1177/1471301210392980

Puchalski, C. M. (2015). Spirituality in geriatric palliative care. *Clinics in Geriatric Medicine*, *31*, 245–252. https://doi.org/10.1016/j.cger.2015.01.011

Seiger Cronfalk, B., Ternestedt, B. M., & Norberg, A. (2017). Being a close family member of a person with dementia living in a nursing home.

Journal of Clinical Nursing, *26*, 3519–3528. https://doi.org/10.1111/jocn.13718

Timmins, F., & McSherry, W. (2012). Spirituality: The Holy Grail of contemporary nursing practice. *Journal of Nursing Management*, *20*, 951–957. https://doi.org/10.1111/jonm.12038

Timmins, F., Neill, F., Griffin, M. Q., Kelly, J., & De La Cruz, E. (2014). Spiritual dimensions of care: Developing an educational package for hospital nurses in the Republic of Ireland. *Holistic Nursing Practice*, *28*, 106–123. https://doi.org/10.1097/HNP.0000000000000015

Toivonen, K., Charalambous, A., & 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*, 880–888. https://doi.org/10.1111/scs.12519

Toivonen, K., Stolt, M., & Suhonen, R. (2015). Nursing support of the spiritual needs of older adults living with dementia. *Holistic Nursing Practice*, *29*, 303–312. https://doi.org/10.1097/HNP.0000000000000101

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*, 349–357. https://doi.org/10.1093/intqhc/mzm042

van Leeuwen, R., & Schep-Akkerman, A. (2015). Nurses' perceptions of spirituality and spiritual care in different health care settings in the Netherlands. *Religions*, *6*(4), 1346–1357. https://doi.org/10.3390/rel6041346

Vincensi, B. B., & Burkhart, L. (2016). Development and psychometric testing of two tools to assess nurse practitioners' provision of spiritual care. *Journal of Holistic Nursing*, *34*, 112–122. https://doi.org/10.1177/0898010114544302

Visser, A., Garssen, B., & Vingerhoets, A. (2010). Spirituality and well-being in cancer patients: A review. *Psycho-Oncology*, *19*, 565–572. https://doi.org/10.1002/pon.1626

Walmsley, B. D., & McCormack, L. (2016). Stigma, the medical model and dementia care: Psychological growth in senior health professionals through moral and professional integrity. *Dementia*, *15*, 1685–1702. https://doi.org/10.1177/1471301215574112

Weathers, E., McCarthy, G., & Coffey, A. (2016). Concept analysis of spirituality: An evolutionary approach. *Nursing Forum*, *51*(2), 79–96. https://doi.org/10.1111/nuf.12128

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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