The Role and Meaning of Spirituality in Older People Living With Dementia: A Systematic Review

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Abstract

Background: Spiritual care is a component of holistic nursing care, and it is a crucial element in providing person-centred care of older people living with dementia. The review aimed to find a deeper meaning and provide a profound interpretation of the role of spirituality from the perspective of older people living with dementia.

Methods: The systematic review was conducted using Preferred Reporting for Systematic Reviews and Meta-Analyses guidelines. Four databases: CINAHL, PubMed, Science Direct, EBSCO host and reference lists were searched for studies published by February 2020. The Qualitative Assessment and Review Instrument were used to assess the quality of studies, and the data were synthesised using thematic analysis.

Results: Ten studies were included in the systematic review. Two main themes: (1) Spirituality as an inner source of power and (2) Spirituality as connectedness described the role and meaning of spirituality in older people living with dementia. Findings show the importance of spirituality as an inner source which gives people with dementia strength in facing dementia and also highlighted the role and meaning of connectedness with self, others and God. Relationships with family and the community is an essential reflection of spiritual life and represent a source of incentive and joy for older people with dementia.

Conclusion: These findings provide new insights based on the qualitative perspective of older people living with dementia. This review offers nursing staff a broader and more in-depth insight into the role and meaning of spirituality as experienced by older people living with dementia and thus encourage the implementation of spiritual care as an integral part of providing holistic person-centred care.

Background

It is well understood internationally that people are living longer, with an increasing incidence of multi-morbidity and an increased likelihood of the need to use hospital and healthcare services. Aside from physical challenges, the frailty associated with longevity means that as people age they are much more likely to avail of these services as they require "special assistance" in their daily lives [1]. The increased risk of dementia is an additional burden associated with longevity that can have a profound impact on a person's quality of life, and also increase the likelihood of engaging with and dependency on health care support [2]. This burden also affects the caregiver, who – although possibly supported within the services – continues to struggle with both the demands of physical and psychological care required, but also the great loss of the person, and their relationship with that person with this condition [2]. Within this context, the prioritisation of physical care needs is common and natural both in hospital and residential care and also in community settings [3]. However, this creates particular gaps in the care of older people with dementia as they may have profound psychosocial needs due to their cognitive decline. People with dementia require a person-centred, relationship-orientated, humane approach and an environment that helps them to connect to their personhood [4]. However, this is often challenging due to

resource constraints [5] even in the domestic setting, because of the demands of caring [6]. As such there are increasing calls for a reorientation of the care for people with dementia, which should focus on the fundamental aspects of care delivery, especially relationships (knowing the person) and providing respectful humane care [7].

As a result, activities are increasingly provided for older people with dementia such as reminiscence therapy, art, gardening music and animal therapy, all with the core aim to provide psychosocial support [8]. However, the experience of dementia can still be very challenging for patients, especially when staff struggle to provide psychosocial support due to resource issues [5]. At the same time, there is increasing recognition of the need to provide spiritual support to patients, particularly to older people whose spiritual beliefs tend to strengthen by a process known as gerotranscendence [9]. This may seem somewhat out of step with a perception of widespread secularism and declining religious beliefs [10]. However, there is increasing evidence that individuals continue to have spiritual beliefs and value their spirituality irrespective of religion's decline in society. This need has also been confirmed by the launch of spiritual care competencies for nurses and midwives in 2019 [11]. As such, spiritual support for older people is something that is gaining attention in published literature [12]. Arguably, providing spiritual support and addressing spiritual needs is something that transcends many psychosocial requirements (such as the need for connection and finding meaning in life). It can also improve quality of life in many ways by providing physical and social activity (by attending church ceremonies, for example) and accessing faith rituals that can be both supportive and reminiscent [13, 14]. The spiritual support offered by Healthcare Chaplains, for example, and other faith groups within the community who have an outreach agenda, could reasonably be utilised, where appropriate, to provide cost-effective psychosocial support. Reciting prayers, for example, has been shown anecdotally to provide great solace to some people with dementia, even in the absence of strong faith, as it reminds them of childhood. That said, there are moral and ethical issues associated with the provision of spiritual and religious care that need consideration in this context.

Understanding spirituality is one such issue, although conflated with religion it is quite a distinct area that, broadly speaking, describes a person's search for meaning in life, their sense of connectedness and the experience of transcendence [15]. Spirituality is not necessarily related to religion, although some people can express it through religious rituals. Spirituality, related to religion or not, can offer a life meaning, particularly at the end of life. Narayanasamy (2006) [16] reported this as a source of inner strength. Indeed, there is no consistent definition of spirituality in the literature [16, 17] but, indeed, definitions go beyond religious and cultural definitions [17]. Spirituality is often associated with an individual's relationship with the world and their personal beliefs [18], their individual and subjective experience of themselves and the dimensions outside of us with the connection of nature and higher powers [15]. McSherry and Smith (2012) [19] loosely describe spirituality as a universal, very personal and individual experience that captures the exclusive ability of each person, as the core and essence of being a person, which permeates the entire structure of a person and a being worthy of dignity and respect. More directly, some researchers [20] define spirituality as a metaphysical life force present in all living beings.

The evidence from research indicates that spirituality is crucial for good health [21]. Since it is strongly associated with well-being [21], higher quality of life and psychosocial experience, reduces the incidence of physical and mental illness, helps people to cope with chronic illnesses, such as dementia [22]. Spirituality does not extinguish with dementia [20].

For people with dementia, dissatisfaction due to physical discomfort, emotional distress, and social isolation can be reflected in the expression of different spiritual needs [17]. Further, physical and mental changes associated with dementia can be perceived as the loss of personhood and oneself [23]. The expression of spiritual needs depends on cultural beliefs and practices as well as personal beliefs and practices [17]. However, spiritual care can significantly improve cognitive ability, and its associated activities can help to raise self-esteem and self-sufficiency in older people with dementia [24]. By satisfying spiritual needs, the effects of stressful events in life can be indirectly reduced, including the fear of the unknown, even death, and help to achieve transcendence and contribute to spiritual development [12]. Therefore, providing spiritual care is crucial in terms of helping people with dementia to cope with the condition [25], which is why the spiritual aspects of nursing are valued in practice. Spirituality enables an individual to find hope, meaning and purpose in life, inner peace; it improves one's sense of satisfaction with life and helps the person to cope with suffering and loss and to connect to one's personhood [26].

Previous reviews about spirituality in people with dementia have focused on different aspects of spirituality. Beuscher and Grando (2009) [27], for example, explored spirituality as a way of dealing with the early stages of Alzheimer's dementia. Kevern (2015) [28] examined features and the impact of spirituality in people with late-stage dementia. Agli et al. (2015) [25] examined those diagnosed with dementia and researched how their spirituality influenced this. Daly et al., (2019) [26] explored the experiences of spirituality for people with dementia from a qualitative perspective. However, to date, no review has specifically explored the role and meaning of spirituality in people with dementia. This systematic review aimed to find a deeper meaning and provide an interpretation of the role of the spirituality of older people with dementia.

Methods

The procedure for this systematic review followed Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [29].

Search strategy

We followed the guidelines of Bettany-Saltikov (2012) [30], who suggested using the PEO approach to create the research question. The research question of this systematic review was: What is the meanings and role (O) of spirituality (E) in people with dementia (P)? The inclusion and exclusion criteria for the review are outlined in Table 1.

The key words for searching the relevant articles were divided into population/problem (P), exposure (E) and outcome (O) as follows: "demen*", "Alzheim*", "elderly", "aged", "aging", "older adults", "old age", "spiritual care", "spirit*", "role", "understand*", "comprehension", "meaning*", "perception*", "view", "viewpoint", "personal view", "opinion", "expression*". The key words were combined with the Boolean operators OR, AND. The MeSH terms search was also used. We determined the articles published in English by February 2020 in the following databases: CINAHL, PubMed, Science Direct, EBSCO host. References cited in systematic reviews were also searched. After key articles were identified, additional searches were conducted using the "Related Articles" search feature in PubMed database. To increase the reliability and academic rigour, after reviewing the full texts, the two authors examined the articles' eligibility and the decision regarding the final inclusion of the articles were done by discussing and achieving agreement between the co-authors.

Selection process

The identified records were screened in three steps. First of all, the identified records were imported into Mendeley manager. After the duplicates were removed the two authors independently evaluated the titles and abstracts against the inclusion and exclusion criteria and those not meeting the inclusion criteria were excluded. We used the Qualitative Assessment and Review Instrument (QARI) to assess the quality of these papers. The QARI quality assessment checklist consisted of 10-items to determine the extent to which a qualitative study addressed the possibility of bias in its research design, conduct and analysis [31]. There is no cut-off point for low or high quality, which is why the checklist was used descriptively rather than analytically. In the checklist, the emphasis has been placed on the links between the philosophical paradigm and research methodology and also on the choice of research methodology and methods, data collection, analysis and the interpretation of findings [31]. All studies meeting the inclusion criteria were assessed for methodological quality by two researchers independently, and disagreements between them was arbitrated by the third author.

Data extraction

Data extraction was based on the aim to find a deeper meaning and to provide an interpretation of the role of the spirituality of people living with dementia. The headings of the extracted data were the following: the place where the study was conducted, sampling, methodology with research design and outcome themes of the study. Data were extracted by three researchers (NMR, ZF, SK), and checked by the leading author (MP).

Data synthesis

The thematic approach [32] was adopted to analyse and synthesise the data in three steps: (1) Line-by-line coding to identify free codes; (2) Organising free codes into descriptive primary and secondary level subthemes; (3) Developing main themes. Discussions were conducted involving all the authors to reach a consensus in naming the two main themes.

Results

During the initial search, 1801 records were identified. After removing duplicates, 1780 articles were screened by title and abstract for their relevance and removed those (n =1727) which did not meet the inclusion criteria. The 53 complete articles were evaluated for eligibility, and 43 articles were excluded, as they did not focus on dementia, spirituality and older people. One study [33] also included relatives, which we nevertheless included in the analysis, as the data analysis in the article was given separately for relatives and people living with dementia. Therefore, ten articles were included in the critical appraisal (Figure 1).

Study quality appraisal

The selected studies met the main considerations relevant to our study. The most common weakness of these studies was in the statement indicating the researcher's theoretical or cultural orientation. Only one study [23] clearly stated the researcher's cultural orientation. Also, there was an evident lack of information regarding the extent to which the researcher influenced the study. The relationship between the participants and the researcher was clearly stated only in two studies [23, 34]. Further, the studies lacked information on reporting congruity between the philosophical perspective and the research methodology as present in Table 2. However, in keeping with guidance on these criteria, and agreement within the research team, all ten studies broadly met the criteria and were retained for closer examination.

Study characteristics

All studies used a qualitative research design. The ethnographic approach [27], phenomenology [23, 35, 36], grounded theory [37] and observation [27, 36, 38] were used. Interview as a data collecting method was used the most frequently [23, 27, 33, 34, 36–40]. Also, focus groups were used for collecting data [33]. Six studies were conducted in the United States, three in Australia and one in Europe. The total sample from all the included studies presents 177 older people with dementia. The detailed descriptions are provided in Table 3.

Understanding spirituality and its meaning in older people living with dementia

Line-by-line coding for all the studies resulted in identification free codes (n=86), developing primary level (n=13), secondary level descriptive themes (n=4) and two main analytical themes: Spirituality as an inner source of power (1) and Spirituality as connectedness (2) (see Table 4).

Spirituality as an inner source of power

Spirituality as an inner source of power was developed from two secondary-level descriptive themes named Facing dementia and Facing oneself.

Facing dementia

Facing dementia was derived from primary-level descriptive themes: Unanswered questions, Insights into the situation; Hope, love, and compassion; Thinking about death.

Unanswered questions

Many of the studies that we have analysed [23, 34, 36, 37, 40] show that people with dementia often ask questions that mostly remain unanswered. The question "why" is widespread: "why me, can I manage, why did I become ill [23], why exactly me [40]?" We further conclude that older people with dementia also ask themselves what they can learn from the illness [23] and how the disease will progress, and what will happen to them [34, 36]. Such questions, which most often remain without answers or satisfying answers, bring older people with dementia unrest, frustration, and feelings of uncertainty [23]. Due to their awareness of mortality, such individuals can, therefore, become even more vulnerable [37].

Insight into the situation

Having to face dementia is often accompanied by bouts of anger and the feeling that they have somehow been wronged [40]. Some other authors, however, report that people with dementia see their situation as an opportunity to mature and grow and that they think the disease may enable their soul to develop spiritually [23, 35]. Spiritual life is an integral part of an individual's life, and that holds true for people with dementia, and therefore the disease has a kind of sense for the person. Living a life in such a way gives rise to a new perspective regarding the situation at hand; the disease gives new meaning and sense to life, and therefore, life, or what remains of it, becomes worth living [23, 36].

Hope, love and compassion

In facing dementia, hope is one of the essential inner sources of power and the reflection of spiritual maturity of older people with dementia, according to numerous studies [23, 27, 33, 40]. Hope is the inner power that gives strength to the older person with dementia to cope with such a severe illness and the resulting situation [40]. At the same time, it helps an older person to accept the disease, recognise new opportunities for which many are also grateful [33, 40]. Hope is the expression of spirituality that offers older people with dementia security and a sense of safety that, despite their illness, the core of who they are will remain intact [23, 40]. Facing the disease can be an opportunity to develop a compassionate attitude towards oneself and the illness - that is spiritual development [23]. Often, older people with dementia become more loving and compassionate to others as well, as they want to help, be useful, serve someone or something, even if their contribution is small [39]. A kind and compassionate attitude, combined with humour, makes it easier for older people with dementia to deal with the disease [23]. Trevitt and MacKinlay (2006) [34] also find that compassion in connection with humour, even at the expense of their forgetfulness, facilitates more open communication between older people with dementia.

Thinking about death

Our results show that thinking about death is not related to being depressed. Older people with dementia can speak about death calmly and in a relaxed manner. Trevitt and MacKinlay (2006) [34] state that older

people with dementia can speak openly about death, as they accept it as a normal process. Often, relatives, nursing staff and other people are those who avoid conversations about death. In addition to open talks about death, results show that older people with dementia are convinced that there is something inconceivable, great waiting for them at the end of life [23, 34].

Facing oneself

Negotiation with self was derived from descriptive themes of primary level; Loneliness; Loss of self and identity; Keeping contact with oneself.

Loneliness

Solitude, loneliness, and sadness are frequent companions of older people with dementia. Even those who live in nursing homes, despite having many opportunities for social contacts, miss family members and relatives who cannot be replaced [34, 37]. Memories of own loss from their early childhood, such as the loss of one's parents or siblings, are often accompanied by feelings of grief which surface daily. Therefore, older people with dementia feel lonely despite being surrounded by people [34]. Older people with dementia are often willing to share their feelings of solitude, grief, and loneliness with other people with dementia; however, often, they have no one to turn to, which deepens their sadness [35, 37].

Loss of self and identity

With the changed experience of oneself, there is a sense of loss that affects perception and experiencing as well as expressing spirituality in older people with dementia [23]. People with dementia become frustrated due to persistent memory problems since they can no longer rely on themselves, which makes them frustrated and makes them feel that they have lost their identity [23, 35]. The results show that dementia takes away people's dignity and degrades them, which leads to despair [23]. We also find that due to the changed perceptions of themselves, their interaction with the environment changes, which also causes various emotional responses, ranging from mild shocks and frustrations to deep feelings of sadness and anger [23]. On the contrary, researchers [36, 37] find that the sufferer does not change at the core and that they remain the same person.

Keeping contact with oneself

Phinney (2011) [36] reports that, despite all the losses, not being able to remember everything and losing some of their knowledge and, consequently, having problems with everyday activities, older people with dementia still feel much the same as they did before the onset of the illness. This is also why engaging with one's spirituality is essential [40], as in order to look at oneself, get in touch with one's thoughts, one has to take time, all of which significantly impacts their life [35]. Spiritual values are maintained despite their disease; however, the modes of expression change. It seems that spiritual values contribute to preserving identity throughout the progression of the disease [23, 35–37].

Spirituality as connectedness

Theme Spirituality as connectedness were developed from two secondary level descriptive themes: Connections with others; Connection with God.

Connections with others

Relationships with others include three descriptive primary-level themes: Friendships; Community and family, and Social isolation.

Friendships

The data analysis shows that joint activities with friends, conversations, relationships with friends, and socialising with them are the critical elements of the spirituality of older people with dementia [23, 35, 38, 39]. Meeting friends at, for instance, religious rituals, is, for some older people with dementia the only way to maintain social contact [38].

Community and family

In addition to friends, an essential reflection of spiritual life is the relationship and connection with family members and the community in which older elderly people with dementia live [23, 33, 39]. Relationships and fostering connections with important individuals, families and the community represent a source of incentive and joy for older people with dementia, which is why they are an essential reflection of spirituality [39]. Interpersonal relations within the family are necessary because of the sense of connection and belonging they evoke [33] and serve as support for older people in dealing with dementia, which is an essential element of spiritual expression [23].

Social isolation

Often, older people who experience dementia avoid social contacts because of the awareness of their cognitive decline, which can cause frustration and agitation [23, 39]. Sometimes, a complete break in social contacts can happen [23]. We also find a decrease in their social contacts, mainly due to their limited ability to maintain interpersonal relationships and to establish new relationships [40].

Connection with God

The connection with God is reflected in three descriptive primary-level themes, namely: Belonging; Deepening the relationship with God; Religion and religious rites.

Belonging

The importance of a sense of belonging to God and the church is emphasised by numerous studies [23, 27, 38, 39]. When going through difficult times, the connection to God is crucial as it helps overcome the fear of the future and provides a sense of security [39]. Participation in religious rites, such as singing at the Mass, gives older people with dementia a feeling that, despite their illness, they are worthy and still belong [27].

Deepening the relationship with God

Their relationship with God is more than something ethereal and abstract because God is their friend who is intimately involved in their daily life and is someone they can always connect with and turn to for support, advice, or a conversation. Some studies report that the disease intensified and deepened their connection to God [23, 39]. The bond with God deepens because they seek and find solace in it, as they are sure that it is always there somewhere, can be counted on and turned to when facing challenges with their memory. They often turn to God for help when they search for things or cannot remember something [33].

Religion and religious rites

Some rites, such as prayer, church visits or meditations can deepen the contact with God [23, 27, 34], which makes it possible for the older people with dementia to function normally [23, 34]. Faith is a constant that remains and deepens even in the face of the disease, or it appears because of it [23].

Discussion

A person's spirituality is one concept that is arguably being forgotten in modern healthcare. Reasons for this may be in the move away from traditional religions, a conflation between spirituality and religion, the discomfort and misfit of a nebulous concept such as spirituality in science-based professions. Nonetheless, nursing academics and others have been researching this field for more than 30 years. What emerges is that nurses believe that patients receiving healthcare support have spiritual care needs which nurses try to address. There is also a growing number of guidelines for nurses so they can carry out spiritual assessment and provide spiritual care. In particular, a European group have recently spent some time developing specific competencies for nurses in health care [11]. These require nurses to support and utilise intrapersonal and interpersonal spirituality, and also assess spiritual needs and provide spiritual care interventions [11].

This is important because spirituality appears to permeate the life of older people with dementia, shaping their life path and seems crucial in the process of discovering and seeking a new meaning in life and inner strength in dealing with dementia. Research show [23, 34, 38, 40] that older people with dementia retain an insight into the experience of spirituality, because deep inside they are still the same people, but are unable and incapable of expressing themselves in the same way as before the disease [23, 34]. Spirituality is a way of manifesting the wholeness of that person living with dementia, helping them to express themselves. Thus, for some, this is an opportunity for spiritual development and enrichment [23].

However, it is important that the spiritual needs of people with dementia are understood. Indeed, a very recent determination of spiritual care competencies for nurses suggests that assessment is crucial [11]. Recent international deliberations in terms of the development of spiritual care competencies for nurses recommend a simple two-step approach by asking: 'What is important to you right now?' and 'How can we help?' [41].

We found that spirituality enables older people with dementia to access their resources deep within, their most profound, hidden powers [23, 36, 40]. In this, faith, hope, love and compassion are essential factors that give a sense of security, power and gratitude. In this search of their internal powers, they do not avoid talking about death and the end of life [34], which they perceive as something unimaginably grand, but at the same time, they see it as something that inspires hope and inner peace [23]. It is also confirmed that older people with dementia often ask themselves questions like "Why I got dementia? Why right me? Will I manage? Why is this happening to me? What am I learning from this experience?" [23, 36, 40]. Such questions are frustrating [23], as they often remain unanswered or begin a series of new issues that cannot be resolved [34, 36]. Furthermore, such questions without the right answers make them vulnerable, as they are aware of their lives are transient [37], and without spiritual care, they do not get adequate support they need and deserve.

Spirituality in older people with dementia plays an exceptional role and is of vital importance in their everyday lives since it enables them to develop the mechanisms they need to deal with and tackle dementia, and awards them the ability to find a new meaning, which affects the quality of their lives. Hope is particularly essential, and it can make it easier to cope with the loss of identity, deal with solitude, loneliness and sadness that they overcome by maintaining contact with their essence, their spirit. Hope is an essential inner factor of spirituality which is highlighted by many authors [27, 33, 34, 36, 40]. It refers to experiencing dementia, to the hope relating to the development of the disease, the hope that they will be able to cope with the consequences of cognitive decline and, last but not least, the hope that death brings inner peace. Hope supports the course of the disease and is reflected in a new attitude towards oneself and the confirmation of one's value and the meaning of life. It follows that elderly people with dementia understand spirituality as a way of finding meaning in their disease, going through illness to life fulfilment.

The main finding of this systematic review is that relationships are critical in the role and meaning of spirituality in people with dementia. Relationships are a common denominator in many concepts of spirituality. These relate primarily to the relationship with oneself, with others, with God, with nature. Relationships relate to hope and the meaning of life and are shaped based on an individual's personal experience. Friends and family are crucial in maintaining interpersonal relationships [23,33,35,39,42,43]. People with dementia describe it as a powerful reflection of spirituality. Maintaining relationships with friends and family is essential, mainly because of the confrontation with the frustration caused by the decline in cognitive functions. Maintaining contact, interpersonal relationships and relationships with their partners imbues them with a sense of security, and at the same time, strengthens the family's connection despite dementia. Therefore, nursing care should be aimed at providing a safe environment, where the older person with dementia feels safe and accepted despite his/her condition. We find, and in this respect, we agree with other studies [34, 36, 38], that relationships are one of the essential elements of spirituality. With this systematic review, we have confirmed the definition of spirituality as defined by Burkhardt and Nagai-Jacobson (2005) [44] spirituality being expressed through association with Source, oneself, others, and nature in various life experiences. Such an in-depth experience of spirituality presents a lifeline in the problematic situations caused by dementia.

Not only the connection with family and partners but also the connection with God [23, 27, 34, 38] is stressed as a vital element of spirituality in older people living with dementia. For some people with dementia, such a connection may be provided by feeling a link to the transcendental [39]. Deepening relationships and faith in people with dementia can be understood as spirituality that remains intact despite the illness that causes a cognitive decline and loss.

Religious rituals, prayers, meditations are the representation of spiritual expression [23, 27, 34]. Some describe [33, 37] that spirituality has deepened and strengthened due to dementia and that is the inner force that gives older people with dementia the power not only to accept the disease but also to face the daily challenges it brings. Religious rituals have been identified as comforting for older people [45]. However, spiritual care must always be individualised and person-centred.

Limitations Of The Review

This systematic review has some limitations. Some relevant literature may have been omitted, as we accessed the English language selection only. The fact that all the included studies had a qualitative research design is another limitation. Furthermore, the methodological quality of studies varied from low to high. The included studies were conducted in very different religious, cultural and social environments, and all the studies, except one, were conducted outside Europe.

Conclusion

This systematic review draws attention to the role and meaning of spirituality from the perspective of older people with dementia. The findings show the importance of spirituality as an inner source of power which gives people with dementia strength in facing dementia and also highlights the role and meaning of connectedness with self, others and God. Friendships and relationship with family and the community is an essential element of spiritual life and represents a source of incentive and joy for older people with dementia. The benefits of this review are providing a new insight into the role and meaning of spirituality as experienced by older people with dementia and implementing spiritual care as an integral part of providing holistic person-centred care.

Relevance to Nursing Practice

Nursing staff need to understand the role and meaning that spirituality has for older people with dementia. These findings provide a wider perspective on understanding spirituality, as it was brought from the experiences of people living with dementia. This could help nursing staff in expanding better awareness of the importance of providing spiritual care for older people living in dementia. These people expect and deserve spiritual support which shapes their life path and appears crucial in the process of discovering and seeking a new meaning in life and inner strength in dealing with dementia. Nursing staff can use findings from this review to improve assessment, planning and spiritual care provision for people

with dementia and thus enhance their daily life, making it more comfortable, secure and giving them with a sense of belonging.

List Of Abbreviations

EPICC: Enhancing Nurses' and Midwives' Competence in Providing Spiritual Care through Innovative Education and Compassionate Care; QARI:Qualitative Assessment and Review Instrument, PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses,PEO: Population, Exposure, Outcome.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Availability of data and materials

The included studies on which the findings and conclusions are made can be found in the references.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

All authors meet the criteria for authorship. NMR performed screening, data extraction and quality appraisal, analysed and synthesised the findings, and drafted the manuscript; ZF performed data extraction and quality appraisal, contributed in drafting manuscript; SK performed screening, data extraction and contributed in data synthesis; FT contributed in data synthesis, drafting manuscript and editing the final version of manuscript; BKP contributed conceptually to the review, and edited the draft manuscript; MP was involved in the design and conception of the review, coordinated review work, and edited the draft manuscript.

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Tables

Table 1: Inclusion and exclusion criteria relating to the PEO research question

PEO parameters	Inclusion criteria	Exclusion criteria
Population	Older people Diagnosis of Dementia	Young adults People not diagnosed with dementia Nurses, Family caregivers, informal caregivers Family members
Exposure	Spirituality	Non-spirituality
Outcome	Meaning Understanding Perception Personal view	Research does not include meaning, understanding, perception, personal view, or experiences of spirituality
Study type	Qualitative methodology design	Quantitative methodology design, Mixed methods Case studies Reviews, meta-synthesis, meta-analysis, Editor letters, Commentaries

Table 2: Critical Appraisal of included studies

Study / Criteria	1	2	3	4	5	6	7	8	9	10	Overall appraisal
Beuscher and Grando [27] 2009	+	+	+	+	+	—	—	+	+	+	Include
Dalby et al.[23] 2011	+	+	+	+	+	+	+	+	?	+	Include
Gardiner [35] 2009	+	+	+	+	+	—	—	+	+	+	Include
MacKinla [36] 2009	+	+	+	+	+	—	—	+	+	+	Include
Mcgee and Myers [37] 2014	—	+	+	+	+	—	—	+	+	+	Include
Phinney [28] 2011	+	+	+	+	+	—	—	+	+	+	Include
Snyder[40] 2003	+	+	+	+	+	—	—	+	?	+	Include
Sullivan and Beard[33] 2014	+	+	+	+	+	—	—	+	+	+	Include
Trevitt and MacKinlay [34] 2006	+	+	+	+	+	—	+	+	+	+	Include
Trevitt and MacKinlay [39] 2004	+	+	+	+	+	—	—	+	+	+	Include
Legend: 1 - Is there congruity between the stated philosophical perspective and the research methodology?; 2 - Is there congruity between the research methodology and the research question or objectives?; 3 -Is there congruity between the research methodology and the methods used to collect data?; 4 -Is there congruity between the research methodology and the representation and analysis of data?; 5 -Is there congruity between the research methodology and the interpretation of results?; 6 -Is there a statement locating the researcher culturally or theoretically?; 7 - Is the influence of the researcher on the research, and vice- versa, addressed?; 8 - Are participants, and their voices, adequately represented?; 9 - Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?; 10 - Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?; + - Yes; — No; ? - Unclear											

Table 3: Overview of included studies

References, country	Objective	Sample	Methodology	Identified themes
Beuscher and Grando [27] (2009) USA	Describes how individuals with early stage of Alzheimer dementia use spirituality to cope with the losses of self-esteem, independence, and social interaction.	15 people with early stage of Alzheimer disease living at home, >65 years	Ethnographic approach, interviews, observations, and field notes	Holding onto personal faith; Seeking reassurance and hope; Staying connected; Effects of Alzheimer disease on spirituality
Dalby et al. [23] (2011) UK	To understand the experience of spirituality in the context of living with dementia, to understand the experience of dementia in the context of spiritual belief	Six people >60 years, aware of the diagnosis of dementia	An exploratory study, semi-structured interview, IPA	Experience of faith; Searching for meaning in dementia; Changes and losses in the experience of the self; Staying intact; Current pathways to spiritual connection and expression
Gardiner [35] (2009) USA	To describe the meaning of spirituality and religion as experienced by older with Alzheimer dementia	Eight older adults with dementia	A Heideggerian interpretative method, Interview-each participant three times	Meaning from occupations; Meaning from interactions with other people; Meaning from organised religious and spiritual activities

References, country	Objective	Sample	Methodology	Identified themes
Mackinlay [37] (2009) Australia	Examines spirituality and meaning in the experience of dementia of older Latvian residents	Three people with dementia living in the nursing home, MMSE scores between 18 and 20, 87-94 years	Grounded theory, In-depth interviews, small group work	<p>Meaning in life;</p> <p>The need for relationship and connectedness,</p> <p>(subthemes of loneliness, grief, the need for emotional and spiritual support, the importance of interactions within the group)</p> <p>The participants' relationship with God and the ways participants responded to meaning through spiritual and religious practices (including attending church services, poetry in Latvian, writing a life story, and response to their environment)</p>
McGee and Myers [39] (2014) USA	To understand the impact and the spiritual dimensions of living with dementia	28 people with moderate Alzheimer's disease	Semi-structured interviews, constant comparative method	<p>The Sacred Remains Important (the transcendent, the spiritual community, significant others, and the Self);</p> <p>Strengthening Sacred Relationships (Identify roles, cultivate walk-alongside relationships, Know the life story, Care for the care partners, create flexible and interactive spiritual experiences, normalise contexts of caring, Provide specialised contexts for participation)</p>
Phinney [36] (2011) USA	To uncover meaning in dementia	Nine people with Alzheimer's disease	<p>Interpretive phenomenological study</p> <p>Interview, field notes, observation</p>	<p>The meaning was unchanged;</p> <p>Finding meaning in new ways of being</p>

References, country	Objective	Sample	Methodology	Identified themes
Snyder [40] (2003) USA	Researching the role of religion and spirituality	28 people with dementia	Interviews, documented verbatim quotes from clinicians, writings from persons with a disease	<p>The role of religion or spirituality in finding meaning in dementia;</p> <p>The role of religion or spirituality in coping with the disease;</p> <p>The influence of dementia on religious or spiritual practices;</p> <p>The influence of dementia on faith</p>
Sullivan and Beard [33] (2014) USA	The role of religion/spirituality in seniors dealing with Alzheimer's dementia	31 seniors diagnosed with early Alzheimer's disease	Individual and group interviews	<p>Trust in god yields strength and hope;</p> <p>Never feeling alone/God as a friend;</p> <p>God helps with memory</p> <p>Keeping a positive attitude;</p> <p>Contentment;</p> <p>The role of churches: social and interpersonal benefits;</p>
Trevitt and MacKinlay [34] (2006) Australia	Exploring spiritual reminiscence	16 residents with a diagnosis of dementia	In-depth interviews, small group discussion	<p>Relationship and meaning (loneliness, family);</p> <p>Attendance at worship (how these combine to give a sense of purpose),</p> <p>Humour;</p> <p>Insight into their illness and living circumstances.</p>
Trevitt and MacKinlay [38] (2004) Australia	To explore the religiosity and spiritual dimension in the life of older people living with dementia	22 participants with a diagnosis of dementia	Semi-structured interviews, observations, and small group sessions	<p>Earliest Memories of religious activities;</p> <p>Relationship with God;</p> <p>Meaning in life</p>

Table 4: Overview of themes and subthemes

Themes	Secondary level descriptive subthemes	Primary level descriptive subthemes
Spirituality as an inner source of power	Facing dementia	Unanswered questions
		Insights into the situation
		Hope, love, and compassion
		Thinking about death
	Facing oneself	Loneliness
		Loss of self and identity
		Keeping contact with oneself
Spirituality as connectedness	Connections with others	Friendships;
		Community and family
		Social isolation
	Connection with God	Belonging
		Deepening the relationship with God
		Religion and religious rites

Figures

Figure 1

Flow chart illustrates the search process[29]

Supplementary Files

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- [Additionalfile1Electronicsearchstrategy.docx](#)
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