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11 The role and meaning of spirituality in older people living with dementia: a systematic review of qualitative studies

Abstract

Background: Spiritual care can improve the cognitive ability and the associated activities, and help raise self-esteem and self-sufficiency in older people with dementia. It creates hope, helps find purpose and inner peace, and improve their sense of satisfaction with life. Thus, spirituality is a crucial element in providing nursing care for older people. This chapter aims to present the role and meaning of spirituality for people with dementia.

Methods: Systematic review of qualitative studies was performed. CINAHL, PubMed, Science Direct, EBSCO host databases, and reference lists were searched for studies published until April 2021. The Qualitative Assessment and Review Instrument was used to assess the quality of studies. Data was synthesized using thematic analysis.

Results: Ten studies were included. Two main themes: (1) spirituality as an inner source of power; and (2) spirituality as connectedness, described the role and meaning of spirituality.

Discussion: Spirituality is an inner source that gives people with dementia the strength to face dementia. It highlights the role and meaning of connectedness with the self and with others. Relationships with family and the community are essential reflections of spiritual life, and represent a source of incentive and joy for older people with dementia.

Keywords: spirituality, older people, dementia, systematic review

11.1 Introduction

It is well understood internationally that people live longer, with an increasing incidence of multi-morbidity and an increased likelihood of using hospital and healthcare services. The increased risk of dementia is an additional burden associated with longevity that can profoundly impact a person's quality of life and increase the likelihood of engaging with the healthcare system and being dependent on its support [1, 2]. Physical care needs are prioritized in hospitals, residential, and community settings [3]. However, this care creates gaps in the care of older people with

dementia as they may have profound psychosocial and spiritual needs due to their cognitive decline.

People with dementia require a person-centred and relationship-orientated humane approach, and an environment that helps them connect to their personhood [4, 5]. 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 and providing respectful, humane care [6]. Understanding spirituality is one such issue. Although conflated with religion, it is quite a distinct area that describes a person's search for meaning in life, their sense of connectedness, and the experience of transcendence [7]. There is no consistent definition of spirituality in literature, but definitions go beyond religious and cultural definitions [8]. Spirituality is often associated with an individual's relationship with the world and their personal beliefs [9], their individual and subjective experience of themselves and with the dimensions outside, and of the connection with nature and higher powers [7]. Spirituality is described as a universal, very personal, and individual experience that captures each person's exclusive ability, 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 [8].

Expressing spiritual needs depends on cultural beliefs and practices, and personal beliefs and practices. However, spirituality does not extinguish dementia [10]. For people with dementia, dissatisfaction due to physical discomfort, emotional distress, and social isolation may be reflected in the way they express their different spiritual needs [8]. Further, physical and mental changes associated with dementia can be perceived as the loss of personhood and oneself [11]. The effects of stressful events in life can be indirectly reduced by satisfying their spiritual needs, including the fear of the unknown, even death, and help achieve transcendence and contribute to their spiritual development [12]. Spirituality enables an individual to find hope, meaning, and purpose in life and inner peace; it improves one's sense of satisfaction with life, helps them cope with suffering and loss, and connects to one's personhood [13]. Therefore, providing spiritual care is crucial in helping people cope with their dementia condition [14], which is why the spiritual aspects of nursing are valued in practice. As such, spiritual support for older people is gaining attention in the published literature [12].

Previous reviews about spirituality in people with dementia have focused on the different aspects of spirituality. Spirituality as a way of dealing with the early stages of Alzheimer's dementia was explored [15], and its features and its impact on people with late-stage dementia was examined [16]. Furthermore, how spirituality influenced people diagnosed with dementia [14] was researched and the spiritual experiences of people with dementia was explored from a qualitative perspective [13]. However, no review has specifically examined the role and meaning of spirituality in people with dementia to date. The chapter aimed to find meaning and interpret the role of the spirituality on older people with dementia.

11.2 Methods

A systematic review, followed by a thematic synthesis of qualitative research [17], was carried out. Meta-synthesis is the interpretative integration of findings from qualitative studies and allows a new interpretation of the research phenomenon [18]. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed for reporting [19].

11.2.1 Search strategy

The PEO approach guidelines were used to create the research question [20]. The research question of this systematic review was: What is the meaning and role (O) of Spirituality (E) in people with dementia (P)? The inclusion and exclusion criteria for the review are outlined in Tab. 11.1.

Tab. 11.1: 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
Exposure	Spirituality	Non-spirituality
Outcome	Meaning Role	Research does not include meaning and role
Study type	Qualitative methodology design	Quantitative methodology design, mixed methods, case studies Reviews, meta-synthesis, meta-analysis, Editor letters, commentaries

The search was conducted using search terms in the English language: dementia, older adults, spiritual, meaning, and role, with their synonyms and Boolean operators. The final search was run as: ((demen* OR Alzheim*) AND (elderly OR “older adults” OR “older people”) AND (“spiritual care” OR spirit*) AND role AND meaning*). The MeSH terms search was also used. We determined the articles published in English between 1990 and April 2021 in the following databases: CINAHL, PubMed, Science Direct, EBSCO host. After the key articles were identified, additional searches were carried out using the “Related Articles” search feature in the PubMed database. Reference lists of included studies were also searched.

11.2.2 Selection process

The identified records were screened in three steps. First, the identified papers were imported into the Mendeley program. After 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 [21]. All studies meeting the inclusion criteria were independently assessed for methodological quality by the two researchers, and the co-authors arbitrated disagreements between them.

11.2.3 Data extraction and synthesis

Data extraction was based on the aim to find a deeper meaning and interpret the role of the spirituality of people living with dementia. The extracted data's headings were the following: the place where the study was conducted, sampling, methodology with research design, and the outcome themes. Data was extracted by three researchers and subsequently checked by the lead author. The thematic approach [17] was adopted to analyse and synthesize the data in three steps: (1) Line-by-line coding to identify free codes; (2) organizing free codes into descriptive primary and secondary level subthemes; and (3) developing main themes. Discussions involving all the authors were conducted to reach a consensus on naming the two main themes.

11.3 Results

During the initial search, 1,654 records were identified. After removing duplicates, 1,633 articles were screened for relevance, by title and abstract, and removed those ($n = 1,580$) that did not meet the inclusion criteria. Fifty-three complete articles were evaluated for eligibility, and 43 articles were excluded as they did not focus on dementia, spirituality, and older people. One study [22] also included relatives, which we nevertheless included in the analysis, as the data analysis in the article was given separately for relatives and for people living with dementia. In this manner, ten articles were included in the critical appraisal (Fig. 11.1).

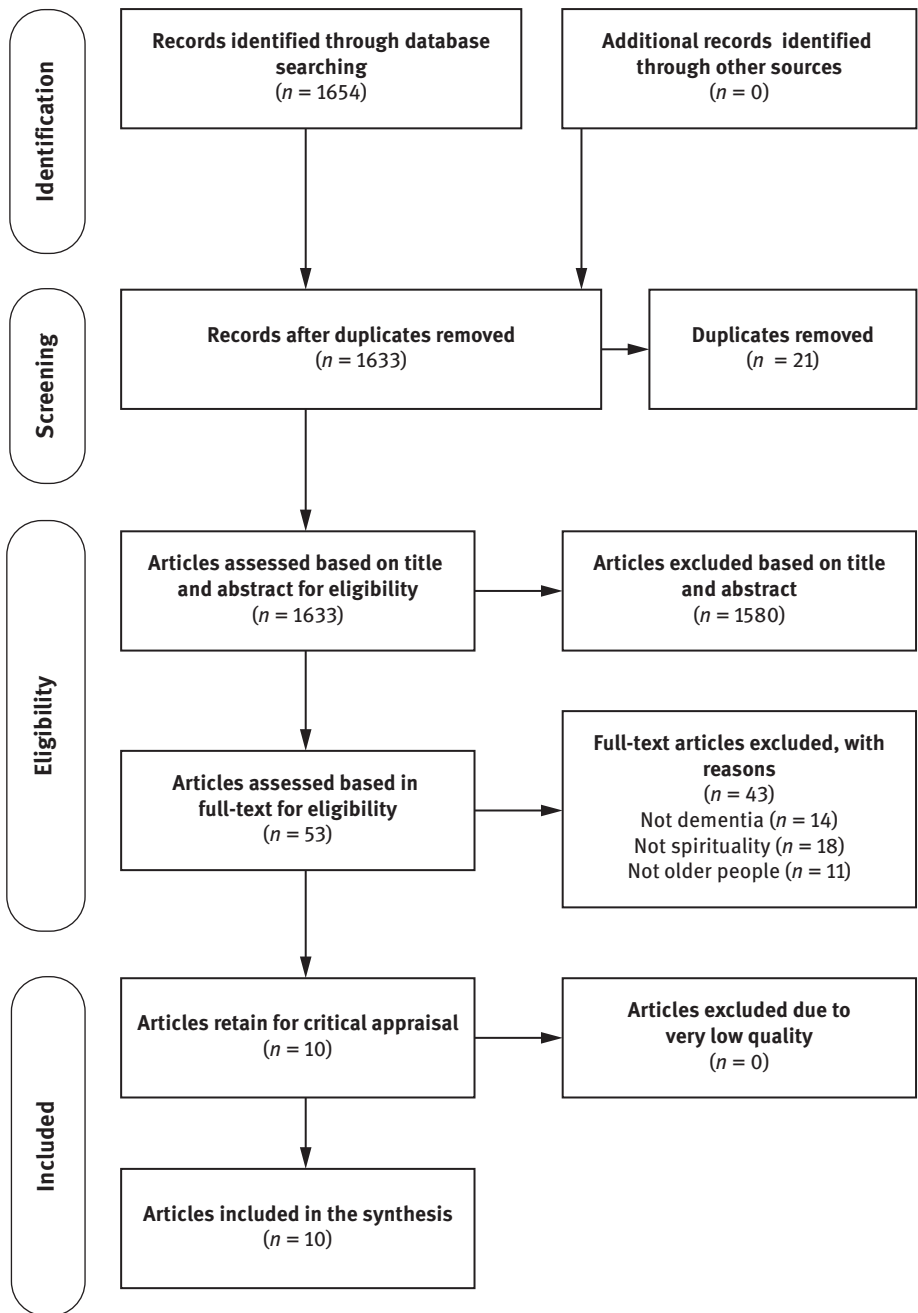


Fig. 11.1: The flow chart illustrates the search process [19].

11.3.1 Study quality appraisal

The selected studies met the primary considerations relevant to our research. The studies' most common weakness was in the statement –the researcher's theoretical or cultural orientation. Only one study [11] clearly stated the researcher's cultural orientation. Also, there was an evident lack of information regarding how the researcher influenced the study. The relationship between the participants and the researcher was clearly stated only in two studies [11, 23]. Further, the studies lacked information on reporting the congruity between the philosophical and research methodologies, as presented in Tab. 11.2. 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.

Tab. 11.2: Critical appraisal of included studies.

Study/criteria	1	2	3	4	5	6	7	8	9	10	Overall appraisal
Beuscher and Grando [15]	+	+	+	+	+	–	–	+	+	+	8/10
Dalby et al. [11]	+	+	+	+	+	+	+	+	?	+	9/10
Gardiner [24]	+	+	+	+	+	–	–	+	+	+	8/10
MacKinlay [25]	+	+	+	+	+	–	–	+	+	+	8/10
McGee and Myers [26]	–	+	+	+	+	–	–	+	+	+	7/10
Phinney [27]	+	+	+	+	+	–	–	+	+	+	8/10
Snyder [28]	+	+	+	+	+	–	–	+	?	+	7/10
Sullivan and Beard [22]	+	+	+	+	+	–	–	+	+	+	8/10
Trevitt and MacKinlay [23]	+	+	+	+	+	–	+	+	+	+	9/10
Trevitt and MacKinlay [29]	+	+	+	+	+	–	–	+	+	+	8/10

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 the 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 the participants and their voices adequately represented?

9: Is the research ethical, according to the 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.

11.3.2 Study characteristics

All studies used a qualitative research design – ethnographic approach [15], phenomenology [11, 24, 27], grounded theory [25], and observation [15, 27, 29]. Interview, as a data collecting method, was used the most frequently [11, 15, 22, 23, 25–29]. Also, focus groups were used for collecting data [22]. 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. Detailed descriptions are provided in Tab. 11.3.

11.3.3 Understanding spirituality and meaning in older people living with dementia

Line-by-line coding of all the studies resulted in the identification of free codes ($n = 86$). Based on that the free codes, we developed primary subthemes ($n = 13$), secondary subthemes ($n = 4$) and two main themes: (1) spirituality as an inner source of power and (2) spirituality as connectedness (Tab. 11.4).

Spirituality as an inner source of power

First main them, *Spirituality as an inner source of power*, was developed from two secondary subthemes: (1) facing dementia and (2) facing oneself.

Facing dementia: Having to face dementia is often accompanied by bouts of anger and the feeling that they have somehow been wronged [28]. However, some authors report that people with dementia see their situation as an opportunity to mature and grow, and think that the disease may enable their souls to develop spiritually [11, 24]. Many studies we analysed [11, 23, 25, 27, 28] 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 [11], why exactly me [28]?” Such questions often remain without answers or satisfying answers, bringing unrest, frustration, and uncertainty to older people with dementia [13]. Due to their awareness of mortality, such individuals can become even more vulnerable [25].

In facing dementia, hope is one of the essential inner sources of power and reflects the spiritual maturity of older people with dementia, according to numerous studies [11, 15, 22, 28]. 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 [28]. At the same time, it helps an older person to accept the disease and recognize new opportunities for which many are also grateful [22, 28]. Hope is the expression

Tab. 11.3: Overview of the included studies.

References, country	Objective	Sample	Methodology	Identified themes
Beuscher and Grando [15], USA	Describes how individuals with early stages of Alzheimer's dementia use spirituality to cope with the losses of self-esteem, independence, and social interaction	15 people with early stage of Alzheimer's disease living at home, >65 years	The ethnographic approach, interviews, observations, and field notes	Holding onto personal faith; seeking reassurance and hope; staying connected; effects of Alzheimer's disease on spirituality
Dalby et al. [11], UK	To understand the experience of spirituality in the context of living with dementia	6 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; current pathways to spiritual connection and expression
Gardiner [24], USA	To describe the meaning of spirituality and religion, as experienced by older with Alzheimer's dementia	8 older adults with dementia	A Heideggerian interpretative method; interview each participant three times	Meaning from occupations; meaning from interactions with other people; meaning that organized religious and spiritual activities
MacKinlay [25], Australia	Examines spirituality and meaning in the experience of dementia of older Latvian residents	3 people with dementia living in a nursing home, MMSE scores between 18 and 20, 87–94 years	Grounded theory, in-depth interviews, small group work	Meaning in life; the need for relationship and connectedness, the participants' relationship with God and the ways participants responded to meaning through spiritual and religious practices

McGee and Myers [26], 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	The Sacred Remains Important (the transcendent, the spiritual community, significant others); strengthening sacred relationships (identify roles, cultivate walk-alongside relationships, know the life story, create flexible and interactive spiritual experiences, normalize caring)
Phinney [27], USA	To uncover meaning in dementia	9 people with Alzheimer's disease	Interpretive phenomenological study; interview, field notes, observation	The meaning was unchanged; finding meaning in new ways of being
Snyder [28], USA	Researching the role of religion and spirituality	28 people with dementia	Interviews, documented verbatim quotes from clinicians, writings from persons with a disease	The role of religion or spirituality in finding meaning in dementia; the role of religion or spirituality in coping with the disease; the influence of dementia on religious or spiritual practices; the influence of dementia on faith
Sullivan and Beard [22], 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	Trust in God offers strength and hope; Never feeling alone/God as a friend; God helps with memory; keeping a positive attitude; contentment; the role of churches: social and interpersonal benefits

(continued)

Tab. 11.3 (continued)

References, country	Objective	Sample	Methodology	Identified themes
Trevitt and MacKinlay [23], Australia	Exploring spiritual reminiscence	16 residents with a diagnosis of dementia	In-depth interviews, small group discussion	Relationship and meaning (loneliness, family); attendance at worship (how these combine to give a sense of purpose), humour; insight into their illness and living circumstances
Trevitt and MacKinlay [29], Australia	To explore the religious 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	Earliest memories of religious activities; relationship with God; meaning in life

Tab. 11.4: Overview of themes and subthemes.

Themes	Secondary subthemes	Primary subthemes
Spirituality as an inner source of power	Facing dementia	Unanswered questions
		Insights into the situation
		Hope and compassion
	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

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 [11, 28].

Our results show that thinking about death is not related to being depressed. Older people with dementia can speak about death, calmly and without being stressed. Older people with dementia can talk openly about death, as they accept it as a normal process [23]. In addition to open talks about death, results show that older people with dementia are convinced that there is something inconceivable great that is waiting for them at the end of life [11, 23].

Facing oneself: Memories of personal loss from their early childhood, such as the loss of one's parents or siblings, are often accompanied by feelings of grief that surface daily. Therefore, older people with dementia feel lonely, despite being surrounded by people [23]. Older people with dementia are often willing to share their feelings of solitude, grief, and loneliness with other people with dementia; however, they usually have no one to turn to, which deepens their sadness [24, 25].

With their changed experience, there is a sense of loss in older people with dementia that affects their perception and experience, finding expression in spirituality [11]. People with dementia become frustrated due to their persistent memory problems since they can no longer depend on themselves, making them frustrated and they feel that they have lost their identity [24]. The results show that dementia takes away people's dignity and degrades them, which leads to despair [11]. We

also find that their interaction with the environment changes due to the changed perceptions, which also causes various emotional responses, ranging from mild shocks and frustrations to deep feelings of sadness and anger [11].

Older people with dementia still feel much the same as before the onset of the illness, despite all the losses, not remembering everything and losing some of their knowledge and, consequently, having problems with everyday activities [27]. Therefore, it is also a reason why engaging with one's spirituality is essential [28]. Looking at oneself to connect with one's thoughts, one has to take time, all of which significantly impact their life [24]. Spiritual values are maintained despite their disease; however, the modes of expression change. Spiritual values preserve identity throughout the disease progression [11, 24, 25, 27].

Spirituality as connectedness

The second main theme, *Spirituality as connectedness*, was developed from two secondary subthemes: (1) connections with others; and (2) connection with God.

Connections with others: The data analysis shows that joint activities, conversations, relationships with friends, and socializing are critical elements of older people's spirituality with dementia [24, 26, 29]. Meeting friends, for instance, at religious rituals is, for some older people with dementia, the only way to maintain social contact [29].

In addition to friends, an essential reflection of spiritual life is the relationship and connection with family members and the community in which older people with dementia live [11, 22, 26]. Relationships and fostering connections with influential 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 [26]. Interpersonal relations within the family are necessary because of the sense of connection and belonging they evoke [22]. They serve as support for older people dealing with dementia – an essential spiritual expression [11].

Often, older people who experience dementia avoid social contact because of the awareness of their cognitive decline, which can cause frustration and agitation [11, 26]. Sometimes, a complete break in social connections can happen [11]. We also find a decrease in their social contacts, mainly due to their limited ability to maintain interpersonal relationships and establish new relationships [28].

Connection with God: The importance of a sense of belonging to God and the church is emphasized by numerous studies [11, 15, 26, 29]. When going through difficult times, the connection to God is crucial as it helps overcome the fear of the future and offers a sense of security [26]. Participation in religious rites, such as singing at Mass, gives older people with dementia, a feeling that, despite their illness, they are worthy and still belong [15].

Their relationship with God is more than something ethereal and abstract. God is their friend who is intimately involved in their daily lives 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 with God [11, 22]. Their 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 searching for things or when they cannot remember something [22].

Some rites, such as prayer, church visits, or meditations, can deepen the contact with God [11, 15, 23], making it possible for older people with dementia to function normally [11, 23]. Faith is a constant that remains and deepens even in the face of the disease or appears because of it [11].

11.4 Discussion

In older people with dementia, spirituality plays a unique role. It is vital in their everyday lives since it enables them to develop the mechanisms they need to deal with and tackle dementia, and provides them the ability to find a new meaning, which affects the quality of their lives.

Therefore, spirituality permeates older people's lives, shaping their life paths and seems crucial in discovering inner strength in dealing with dementia and seeking new meaning in life. Our findings show that older people with dementia retain insights into their experience with spirituality. Deep inside, they are still the same people but are unable to and are incapable of expressing themselves in the same way as they could, before the disease. Spirituality is a way of manifesting the wholeness of that person living with dementia, helping them express themselves. Thus, this is an opportunity for their spiritual development and enrichment [11].

We found that spirituality enables older people with dementia to access their resources deep within their most profound, hidden powers [11, 27, 28]. Faith, hope, love, and compassion are essential factors that give a sense of security, power, and gratitude. In this search for their internal powers, they do not avoid talking about death and about end of life [23], which they perceive as something unimaginably grand, but at the same time, they see it as something that inspires hope and inner peace [11].

Hope is incredibly essential. It can make it easier for older people to cope with their loss of identity and deal with solitude, loneliness, and sadness, which they overcome by maintaining contact with their essence, their spirit. Hope is an essential inner factor of spirituality that is highlighted by many authors [15, 22, 27]. It refers to experiencing dementia, to the hope relating to the progression of the disease, the hope that they will be able to cope with the consequences of cognitive decline, and finally, the hope that death brings inner peace. Hope supports the course of the

disease. It is reflected in a new attitude towards oneself, and the confirmation of one's values and the meaning of life. Older people with dementia understand spirituality by finding meaning in their disease and going through illness to life fulfilment.

It is also confirmed that older people with dementia often ask themselves questions such as: "Why I got dementia? Why right me? Will I manage? Why is this happening to me? What am I learning from this experience?" [11, 27, 28]. Such questions are frustrating [11], as they often remain unanswered or they raise a series of new issues that cannot be resolved [23, 27]. Such questions without the right answers make them vulnerable as they are aware that their lives are transient, and without spiritual care, they do not get the support they need and deserve. The spiritual needs of people with dementia must be understood. Indeed, the assessment of spiritual needs is crucial [30]. The researcher recommends a simple two-step approach by asking: "What is important to you right now?" and "How can we help?" [31].

This review's main finding is that relationships are critical in spirituality's role and meaning in people living with dementia. Relationships are a common denominator in many concepts of spirituality. These primarily relate to relationships with oneself, others, God, and 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 [22, 24, 26]. People with dementia describe relationship with friends and family as a powerful reflection of spirituality. Maintaining relationships with friends and family is essential, mainly because of their fight with the frustration caused by the decline in cognitive functions. Maintaining contact, interpersonal relationships, and relationships with their partners imbue them with a sense of security and, at the same time, strengthens the family's connection, despite dementia. Therefore, nursing care should provide a safe environment where the older person with dementia feels safe and accepted despite his/her condition. In this respect, we agree with the other studies [23, 27] that relationships are essential elements of spirituality.

The connection with family and the relationship with God [32] are stressed as essential elements of spirituality in older people living with dementia. For some people with dementia, such a connection may be provided by the feeling of a link to the metaphysical [32]. Religious rituals, prayers, and meditations represent spiritual expression [15, 23]. Deepening relationships and faith in people with dementia can be understood as spirituality that remains intact despite the illness, which causes cognitive decline and loss. In this way, deepening and strengthening spirituality presents an inner force that gives older people with dementia the power to accept the disease and face the daily challenges.

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

11.5 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 that gives people with dementia, the strength to face it, and highlights the role and meaning of connectedness with the self, others, and God. Friendships and relationships with family and the community are essential elements of spiritual life, and represent a source of incentive and joy for older people with dementia. The benefits of this review are, providing 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.

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