

The experience of spirituality from the perspective of people living with dementia: A systematic review and meta-synthesis

Dementia

0(0) 1–23

© The Author(s) 2016

Reprints and permissions:

sagepub.co.uk/journalsPermissions.nav

DOI: 10.1177/1471301216680425

journals.sagepub.com/home/dem

Louise Daly, Elizabeth Fahey-McCarthy and Fiona Timmins

School of Nursing and Midwifery, Trinity College Dublin, Ireland

Abstract

Spirituality is an important aspect of humanity. Concerned with deriving meaning from events, and connection with others, it provides a mechanism for some to cope with illness and disability. While spiritual support is recognised as important, little is known about the spiritual needs of those people experiencing dementia. This meta-synthesis considers the experiences of spirituality from the perspective of people living with a diagnosis of dementia. Using a review protocol, key words from a preliminary scoping review were used to direct database searches in November 2013. A total of 667 papers were initially identified. However, following careful quality review assessment a final eight papers were selected. Findings demonstrated the ongoing importance of spirituality to people living with dementia and its importance as a means of finding hope, meaning and linkage with past, present and future. Expression of spirituality through faith practices, contact with faith communities, and the impact of dementia on these, were also highlighted.

Keywords

dementia, experience, spirituality, systematic review

Introduction

The term spirituality is derived from Latin and refers to ‘breath of life’ (Brillhart, 2005, p. 31). Spirituality is frequently conceptualised in terms of being at the core of who we are (Eliopoulos, 2014; Frankl, 1963; Narayanasamy, 2010). While no universally agreed definition is available, we believe the description presented by McSherry (2009, cited in McSherry & Smith, 2012), is particularly apt in relation to dementia, as it is not reliant on intellectual capacity, whereas others require cognitive awareness to experience

Corresponding author:

Louise Daly, School of Nursing and Midwifery, Trinity College Dublin, 24 D'Olier Street, Dublin 2, Ireland.

Email: louise.daly@tcd.ie

spiritual needs (Weathers, McCarthy, & Coffey, 2015). This description suggests spirituality is:

universal, deeply personal and individual; it goes beyond formal notions of ritual or religious practice to encompass the unique capacity of each individual. It is at the core and essence of who we are, that spark which permeates the entire fabric of the person and demands that we are all worthy of dignity and respect. It transcends intellectual capability, elevating the status of all humanity to that of the sacred. (McSherry, 2009, cited in McSherry & Smith, 2012, p. 118)

Bell and Troxel (2001, p. 32) assert that ‘ultimately, spiritual issues are important because all of us have spirits that shine when given attention or become dull if neglected’. Thus, spiritual support of service users where there is an assessed need is an important component of health and social care. However, a neglect of the spiritual is an acknowledged concern in contemporary healthcare settings (MacKinlay, 2012). Our experience, similar to that highlighted by Powers and Watson (2011), is that people with dementia in particular may not experience sufficient support in this aspect of care. One reason for this is that supporting spirituality involves understanding a person’s individual spiritual needs and how to meet them, which can be difficult particularly as dementia advances. This can be further complicated in circumstances where dementia care practitioners lack sufficient knowledge, experience or skills to address such needs. Such a deficit in care risks spiritual distress (Daly & Fahey-McCarthy, 2014) and potentially the infliction of spiritual harm on the person with dementia. Spiritual distress is understood as impaired ability to connect with others and to derive meaning from life (Caldeira, Carvalho, & Vieira, 2013). This can result in a destruction of values, lack of respect for values, cultures and differences and the removal of hope (Carroll & Shaw, 2013). Although the importance of spirituality for older people in healthcare has been clearly identified (MacKinlay, 2006, 2012), the experience of spirituality from the perspective of those with dementia has undergone limited exploration. This is of concern as it is important to understand the experience of spirituality for those living with dementia as a first step in designing dementia care interventions that uphold spirituality. The purpose of this systematic review therefore was to answer the following question: ‘What are the experiences of spirituality from the perspective of people living with a diagnosis of dementia?’

Methods

Systematic reviews occupy a vital role in the process of making sense of research findings to inform healthcare decisions through the ‘identification, critical appraisal and summary of evidence’ (Handoll & Smith, 2004, p. 227). They are a key contributor to evidence-based healthcare (Khan, Kunz, Kleijnen, & Antes, 2003). Meta-synthesis is a particular systematic review approach to the synthesis of the findings of qualitative research studies with the intent to produce a new or expanded understanding or interpretation of a pre-defined research question (Cooke, Smith, & Booth, 2012; Korhonen, Hakulinen-Viitanen, Jylha, & Holopainen, 2013). According to Korhonen et al. (2013), the synthesis of qualitative research introduces a patient or person-focused standpoint to evidence-based practice.

The term meta-synthesis is used to refer to a number of differing approaches to the synthesis of qualitative research, including thematic synthesis (Hannes & Lockwood, 2011), meta-aggregation (Korhonen et al., 2013; The Joanna Briggs Institute, 2011); and meta-ethnography. This meta-synthesis employed a meta-ethnographic approach, which

focuses on generating new knowledge through interpretation to produce theory or explanatory models (Booth, Papaioannou, & Sutton, 2012; Noblit & Hare, 1988). The form of meta-ethnography that was found to be most applicable in the current systematic review was reciprocal translation in which concepts or metaphors across studies are similar or new metaphors can be used to apply to interpretations from a set of studies (Noblit & Hare, 1988; Thorne, Jensen, Kearney, Noblit, & Sandelowski, 2004). A systematic review protocol was devised by the review team to inform the conduct of the review. The components of this protocol were not altered during the systematic review process, so that faithfulness to the aim of the systematic review was ensured.

Aim and objectives

The aim of this systematic review was to establish the experience of spirituality from the perspective of people living with dementia. The specific objectives were:

- To review the available empirical evidence relating to the experience of spirituality from the perspective of the person living with dementia.
- To collect data on the experience of spirituality from the perspective of the person living with dementia.
- To produce an interpretation of the research phenomenon.
- To integrate the retrieved data to produce a new higher order interpretation of the experience of spirituality in dementia with which to enhance understanding.

Inclusion and exclusion criteria

Inclusion and exclusion criteria were chosen based on the purpose of the review and not with reference to a particular type of qualitative research (Table 1). This approach to qualitative research synthesis is a means to 'integrate the richness of the qualitative traditions' so as to capture the phenomenon of interest (The Joanna Briggs Institute, 2011, p. 16).

Literature search strategy

A search was conducted of the following electronic databases by two of the researchers: CINAHL, PubMed, PsychInfo, Science Direct, Applied Social Science Index and Abstracts (ASSIA), Social Sciences Index and Web of Science. The keywords used to locate relevant literature were divided into those used to identify the population/problem, exposure and outcome of interest (PEO) (Table 2) (Bettany-Saltikov, 2012). The search strategy was constructed with expert advice from a subject librarian and two experienced systematic reviewers within the University.

Each set of keywords was firstly combined using the Boolean operator 'Or' and then the outcome of each set was combined using 'AND'. Where appropriate each database was searched using free text searches and a thesaurus or MeSH search. No timeframe was applied. The only search limitation used was 'English language'. In addition, the indexes of the following journals were searched: *Dementia* The international journal of social research and practice, *Journal of Christian Nursing*, *Journal of Religion and Health*, *Mental Health*, *Religion and Health*, and the *Journal of Holistic Nursing*, as were the

Table 1. Inclusion and exclusion criteria.

Parameters	Inclusion criteria	Exclusion criteria
Population	People or persons with a diagnosis of dementia	People with conditions other than dementia, health and social care professionals, informal carers/family members
Exposure	Spirituality in the presence of dementia	Non-spirituality related research or research exploring spirituality but not spirituality and dementia
Outcome	Perception(s), experience(s) or view(s)	Any research that does not explore perception(s), experience(s), meaning(s) or view(s) of spirituality
Study type	Peer reviewed qualitative research including (but not limited to): interpretive, phenomenology, grounded theory, case study, feminism and narrative research	Experimental or quantitative descriptive research

Table 2. Search terms used to retrieve relevant literature.

Population and problem	Exposure	Outcome
1. Dementia	1. Spirituality	1. Views
2. Cognitive impairment	2. Spiritual	2. Experiences
3. Alzheimer's disease	3. Spirit	3. Perceptions
4. Alzheimer's dementia	4. Religion	
5. Vascular dementia	5. Religiosity	
6. Lewy Body dementia	6. Religious	
7. 'Human Immunodeficiency virus dementia' or 'AIDS and dementia'		
8. Fronto-temporal or frontotemporal dementia		
9. Alcohol dementia or alcohol-related dementia or Korsakoff's disease		

reference lists of all retrieved studies. Figure 1 provides an overview of the search and selection process.

A total of 667 papers were identified. On title and abstract review, 629 papers were excluded on the basis that they did not fit the inclusion criteria for the review. After removing duplicates, the remaining 27 papers were selected for full text review. Fourteen of these papers were further excluded on full reading as they were found not to be primary research or did not relate to the purpose of the systematic review. The final 13 papers were then subjected to a rigorous quality assessment.

Quality assessment

An adapted format of the COREQ 32 item check list was used to facilitate the quality assessment of each of the selected papers. This tool was adapted by Lundgren, Begley, Gross, and Bondas (2012) to include 13 additional items (total 45 items), for example relating to ethical considerations, literature usage and relevance and transferability.

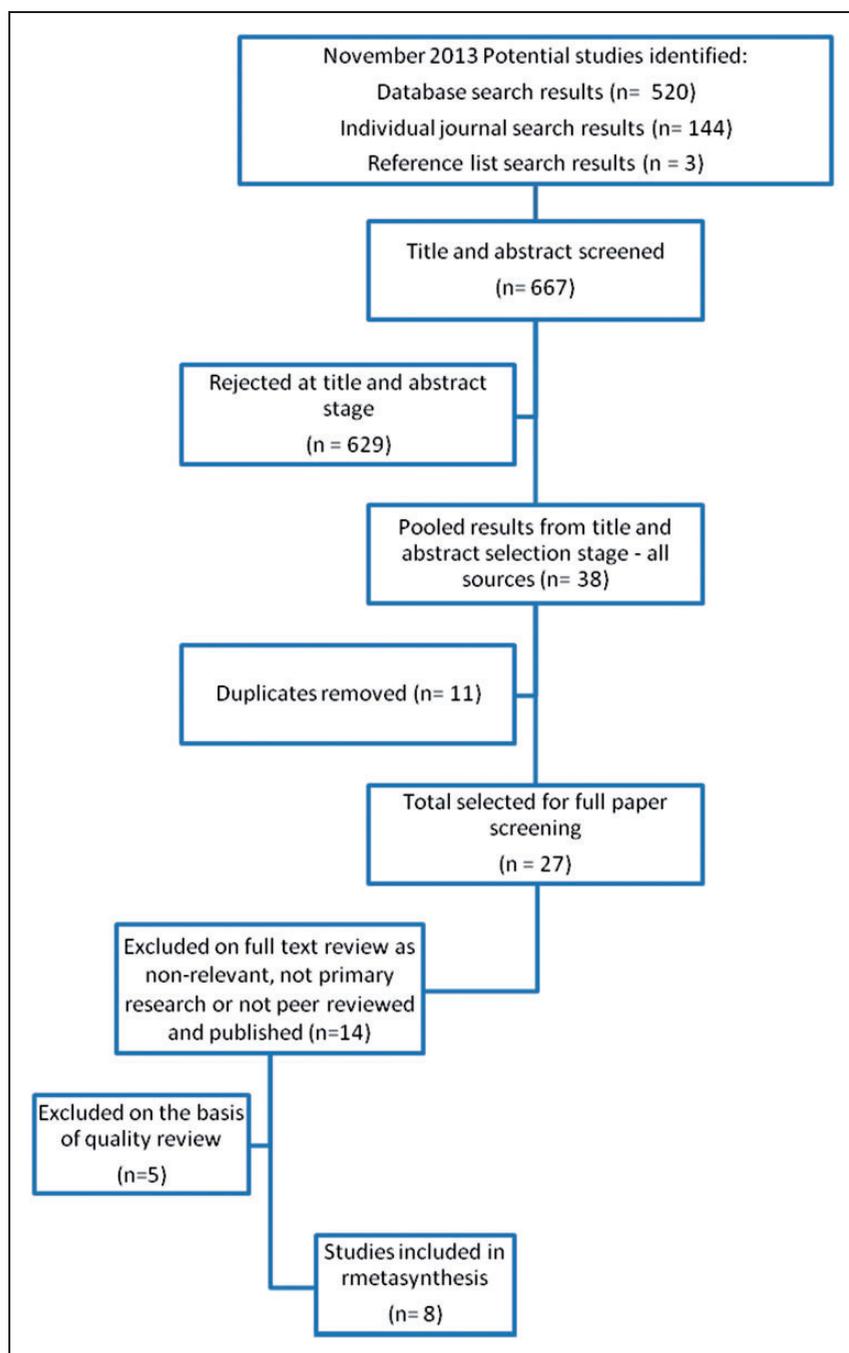


Figure 1. Flow diagram of the search and selection process.

The quality assessment of each study was conducted independently by two of the systematic review team who then met to agree each study's inclusion or exclusion. Where questions arose around suitability for inclusion ($n = 2$), the third member of the systematic review team reviewed the study and a consensus decision was then made.

Data extraction, analysis and synthesis

To ensure consistency, a standard purpose designed data extraction tool was used to extract relevant data from the findings sections of each of the included studies. Firstly each study was read by a member of the systematic review team a number of times to facilitate immersion and to enable the identification of pertinent research findings with which to inform the meta-synthesis. This process enables reviewers to become more cognisant of the participants' worlds and facilitates understanding from their perspectives (Betany-Saltikov, 2012).

Secondly, the extracted data for each included paper was then subjected to content analysis using open coding during which key concepts or interpretive metaphors relevant to the research phenomenon were identified and linked to related text (Booth et al., 2012; Campbell et al., 2003). Once this process was complete, a search for the presence or absence of these concepts or interpretive metaphors was conducted across all eight studies using constant comparison (Tranfield, Denyer, & Smart, 2003). This resulted in an iterative process to synthesise the systematic review findings to produce an expanded holistic interpretation of the experience of spirituality from the perspective of the person with dementia.

Findings

Overview of included studies

A total of eight studies, spanning the years 2003–2013, were included in the meta-synthesis. The authors, study detail and characteristics of each study are displayed in Table 3. None of the studies fell within the high score range, six scored within the medium range and two within the low score range. The two that scored in the low quality range were included because they directly related to the systematic review question and they scored over 20 which the review team felt was acceptable due to the highly rigorous nature of the scoring system in the quality assessment tool. The systematic review team were also conscious that according to Booth et al. (2012, p. 116) 'often studies do not report enough details of the methods of a study and thus the quality assessment measures only the quality of reporting'. However, other studies falling in the low scoring range ($n = 5$) were excluded based on their very low score.

From the eight studies included, one overarching theme and three sub-themes were identified as constituting the experience of spirituality from the perspective of the person with dementia (Figure 2). All of the themes were found to inter-relate with the others as components of the overall experience. The findings of the meta-synthesis will now be discussed with reference to these themes.

Overarching theme: The experience of spirituality in the presence of dementia

This theme conceptualises the point at which spirituality-related experiences of dementia come together to create an overarching and encompassing sense of spirituality in the lives of people with dementia. Although spirituality as a concept was not explicitly presented in

Table 3. Characteristics of included studies.

Paper No:	Author and year	Aim	Methodology	Participants and location	Key findings reported by author
1	Katsuno (2003)	To describe the spiritual experiences of people with early-stage dementia. To explore the relationships between personal spirituality and perceived quality of life.	Descriptive qualitative study using triangulation of qualitative and quantitative methods. Qualitative data collected using semi-structure interview guide.	Purposive sample of 23 people (18 female, 5 male) with dementia recruited via a dementia-specific day-centre and residential setting in an urban area of a mid-western city in the United States. 10 participants were Catholic, 8 Protestant and 5 were described as Jewish.	Overarching theme: Faith in God, six related categories <ul style="list-style-type: none"> • Beliefs. • Support from God. • Sense of meaning/purpose in life. • Private practice. • Public practice. • Changes due to dementia. Overarching themes:
2	Snyder (2003)	To examine the role of religion and spirituality in the lives of persons with dementia.	Qualitative study with data gathered from the researcher's interviews with people with dementia, verbatim quotes from clinicians and recorded in literature, videos and writings from persons with dementia.	28 persons (19 men and 9 women) with Alzheimer's dementia and one person with fronto-temporal dementia. 11 participants were Protestant, 7 Catholics, 3 Christians (unspecified), 3 Jews, 1 Buddhist and 3 non-religious.	Overarching themes: <ul style="list-style-type: none"> • Finding meaning in Alzheimer's. • Coping with Alzheimer's. • The influence of Alzheimer's on faith. • The effect of Alzheimer's on religious or spiritual practice.
3	Beuscher and Grando (2009)	To explore how people with early stage Alzheimer's disease use spirituality to cope with their condition. To explore the spiritual practices that support this. To explore how Alzheimer's	Ethnographic approach involving semi-structured multiple interviews (2 or 3) with each participant. Observation tool to facilitate observation of the home environment for expressions of spirituality and participants'	Purposive sample of 15 people (8 female, 7 male) with early-stage dementia living at home in central Arkansas. All participants reported a Christian religious affiliation (3 Methodist, 4 Baptist, 3 Church of Christ,	Overarching themes: <ul style="list-style-type: none"> • Holding onto personal faith. • Seeking reassurance and hope. • Staying connected.

(continued)

Table 3. Continued.

Paper No:	Author and year	Aim	Methodology	Participants and location	Key findings reported by author
4	MacKinlay (2009)	To examine how people find meaning in the experience of dementia and how they may be supported in this experience.	<p>language, non-verbal communication, movements and affect. Field notes were completed and audio-taped, and then used as data.</p> <p>A grounded theory approach was taken.</p> <p>Questions were based on the model of Spiritual Tasks and Process of Aging (MacKinlay & Trevitt, 2006)</p>	<p>2 Episcopalian, 2 Catholic and 1 Lutheran.</p> <p>Part of a larger study of 113 residents. The study used in-depth interviews and small group work with three individuals over a period of six weeks to collect data. Participants were all Lutherans.</p> <p>Lativan residents in an aged care facility in the Australian Capital Territory (ACT)</p>	<p>Six themes emerged:</p> <ul style="list-style-type: none"> • meaning in life • the need for relationship and connectedness, • participants' relationship with God and the ways participants responded to meaning through spiritual and religious practices • Vulnerability and transcendence • Issues of wisdom and memory, centering around war experiences (World War II) and past work experiences. • Hope and fear
5	Carr, Moore, and Montgomery (2011)	An exploration of the experience of spiritual care via participants' spiritual meanings and experiences.	<p>Hermeneutic phenomenological study using open ended interviews and analysed using thematic analysis as data collection proceeded. Field notes and interview transcripts were analysed.</p>	<p>Total sample included 29 participants purposively selected – people with dementia, families and staff at an urban tertiary care centre in Canada. 8 of the 29 participants were people with moderate to severe dementia. Of these 8 participants, 4 were Roman</p>	<p>Spiritual care in dementia care involved the promotion of personhood through intentional caring attitudes and actions.</p> <p>Findings related to:</p> <ul style="list-style-type: none"> • 'The little things' – simple yet complex. • Giving and receiving.

(continued)

Table 3. Continued.

Paper No:	Author and year	Aim	Methodology	Participants and location	Key findings reported by author
6	Powers and Watson (2011)	The study aimed to: (a) obtain an understanding of residents' spiritual orientations, practices, and preferences; (b) examine family member and NH staff perceptions of spiritual nurturance and support for residents; and (c) analyse institutional resources for and approaches to assessing and meeting residents' spiritual needs.	A mixed method study predominant method was qualitative. Participant observation by the first author (a nurse-anthropologist) and preliminary immersion in each setting to gain familiarity with the culture and establish relationships included attending selected activities, interacting informally, and recording observations in field-notes. Residents' attendance at a variety of 32 randomly observed religious activities was recorded along with their responses to the activity (or reasons for not attending). Visiting, talking with family members and observation were primary means of data collection with the 36 residents (23 women/13 men) unable to communicate in words.	Catholic, 2 Baptist and 2 Anglican. 83 Residents with a diagnosis of dementia were purposefully selected (47 women and 36 men). 31 were Catholic, 24 were Jewish, 23 were Protestant. Other/non-religious = 5. 47 participants who could communicate using words were selected for semi-structured interviews (24 women/23 men). Semi-structured interviews were also conducted with 30 family members and 66 nursing home staff.	<ul style="list-style-type: none"> Barriers to spiritual care in dementia. <p>Main themes emerged in relation to:</p> <ul style="list-style-type: none"> Residents perspectives Lifting spirits Spiritual concerns: prayers, faith, doubt and disillusionment Family and nursing home staff perspectives Need to nurture the spirit within Institutional approaches and resources Facilities and spiritual care providers Preparation and beliefs of nursing home personnel regarding spiritual care.
7	Dalby, Sperlinger, and	To construct an understanding of how older people's experience of spirituality,	Qualitative exploratory design using interpretive	Purposive sample of 6 people with mild to moderate dementia (5 female, 1 male).	Overarching themes: <ul style="list-style-type: none"> Experience of faith. Searching for meaning in

(continued)

Table 3. Continued.

Paper No:	Author and year	Aim	Methodology	Participants and location	Key findings reported by author
	Boddingon (2012)	religion, or faith is affected by dementia. To understand how the spiritual aspects of people with dementia's lives affect the experience of dementia.	phenomenological analysis of interview transcripts.	Four of the participants had Christian belief systems and 2 participants had belief systems aligned with eastern traditions.	dementia. • 'I'm not as I was' – changes and losses in experience of the self. • Staying intact. • Current pathways to spiritual connection and expression.
8	McGee, Myers, Carlson, Funai, and Barclay (2013)	To provide an explanatory model for how spirituality impacts the lives of people with Alzheimer's dementia.	Mixed methods study using a structured interview previously designed by two of the researchers and measures of cognitive, emotional, behavioural and spiritual functioning.	Purposive sample of 28 people, 16 women/12 men. Recruited from two Alzheimer's centres and one person was from a local retirement community in Texas, USA. 20 participants were Protestant, 2 were Catholic, 1 'none' and 1 'other').	Overarching qualitative themes: • Spiritual or religious beliefs as a guide to relating to the world and others. • The importance of infusing spirituality into everyday lives. The role spirituality plays in existential questions post diagnosis of Alzheimer's.

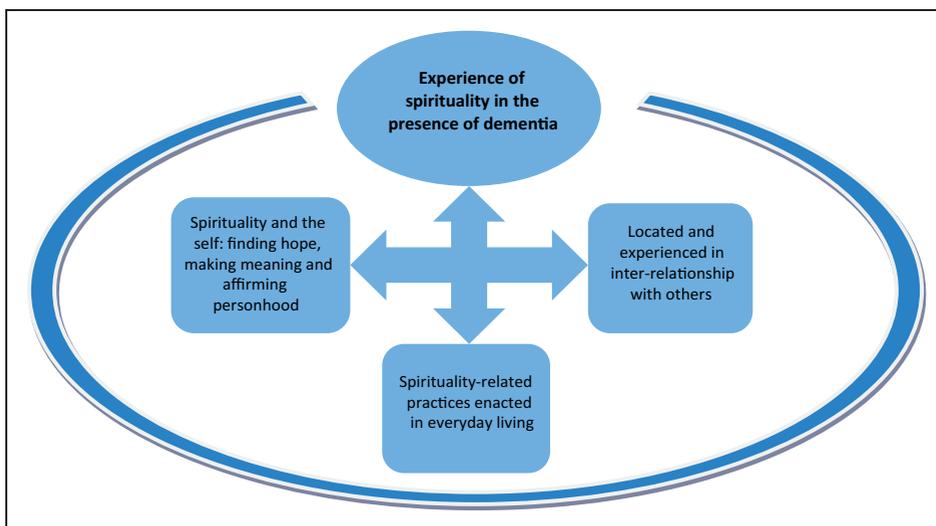


Figure 2. Illustration of themes and sub-themes.

terms of a definition by participants, the importance of spirituality, its nature and its essence in terms of personal meaning to the person, were referred to by participants in all studies (studies 1–8 as listed in Table 3). Data suggested that a sense of the self, and expressions thereof, were indistinguishable from a person’s spirituality and findings in some studies (studies 2, 3, 8) suggested that a sense of the spiritual may be heightened in the presence of dementia:

... their [people with dementia] experience of spirituality seemed to be woven into the fabric of their life, part of them, and therefore dependable and sure. (study 7, p. 82, lines 11–12)

This man later explained that the experience of having AD gave him a heightened spiritual sense. ‘My religion has always been a part of me, and it gets stronger and stronger. It has gotten more intense’. (study 3, p. 59, lines 5–8)

Spirituality was shown to be associated for many with religion, religiosity, transcendence or a connection/relationship with a transcendental being or God who was referred to as a source of strength and/or guidance. Participants in the studies provided examples of how they accessed such guidance, for example through spiritual writings or the seeking and receipt of support through petitions (studies 1, 3, 4, 6, 8). In some studies, reference to a superior being was further expressed in terms of accompaniment and continuity, such that the person with dementia spoke of journeying with this being, which could imply that active engagement with spirituality offers a means of buffering against feelings of abandonment or loneliness, which are often found in research pertaining to the experience of dementia:

...God is there to be a companion through the challenges presented to us in life. (study 2, p. 301 or 2, lines 1–5)

The Lord is with me and beside me all the time. (study 8, p. 234, lines 34–35)

Importantly, spirituality was not experienced in all instances through religion but also through attaining a sense of meaning via connection to life experiences at an emotional and aesthetic level, for example in art or nature (studies 6, 8). Therefore, findings in all studies confirm that rather than being compromised or lost, as could be assumed in dementia, spirituality is ongoing and indeed a pivotal consideration in sustaining the person living with dementia, as shown here:

All the participants described an experience of faith that was a living and active part of their lives.

This seemed to contribute to their sense of themselves as a person. (study 7, pp. 81–82, lines 3–4)

Findings such as these demonstrate that spirituality was shown to be one means to situate the self and remain meaningfully engaged and active within the world as will be developed in the sub-themes below. This does not however imply that the experience of spirituality may not be affected by dementia or that the ways in which a person engages with and expresses their spirituality may not change or be challenged. This is supported in a few of the studies that reported a questioning of faith and beliefs by the person with dementia, and/or experiencing a spiritual crisis or spiritual distress (studies 2, 6). Despite such reports, many of the participants' responses demonstrated that while aspects of one's being in the world can be challenging in the presence of dementia, the experience of spirituality can be a source of strength when faced with the challenges of progressive cognitive impairment. As one participant put it:

Christ is my crutch. He is there to lift me up and walk with me. That is a very strong comfort to me. (study 3, p. 590, lines 10–11)

In summation, spirituality, in this overarching theme, was shown to be a central feature of the person living with dementia's identity and simultaneously a metaphorical comforter, to be cocooned within, offering a sense of familiarity and safety, meaningful engagement, and connection to one's life-course as well as to other people. This overall sense of spirituality was constituted by the sub-themes now presented.

Sub-theme 1: Spirituality and the self – Finding hope, making meaning and affirming personhood

This sub-theme incorporates two subcomponents both of which support the affirmation of the personhood of the person living with dementia. The first of these subcomponents relates to the supportive role and function of spirituality in relation to the provision of hope. Persons with life-limiting illnesses such as dementia need to have hope and to be supported through difficult times. The findings demonstrated that spirituality and its forms of expression are drawn on by people with dementia as active coping mechanisms to this end, particularly by those for whom spirituality was an ongoing part of their life-course (studies 1, 2, 3, 7, 8). Findings suggested that connection with personal spirituality may enable the person living with dementia to foster hope (studies 2, 4, 7), particularly early on in the trajectory of the condition, that in turn may contribute to the preservation of identity. For example whereas dementia is frequently conceptualised as a threat to self and personhood, here in counterbalance spirituality was referred to in terms of the following:

that one's religion or spirituality provided solace by inspiring feelings of hope, strength, security, or guidance. (study 2, p. 304, lines 9–11)

Furthermore, prayer was comforting and gave hope to these participants. For example one woman shared, 'I pray every night and I always feel better after I do that. It gives me hope'. (study 3, p. 590, lines 20–23)

This finding was further supported by data that elucidated the ways in which spirituality acted as a source of solace and comfort to those seeking acceptance or a reason for what they as a person were experiencing:

Trust in God. Some Participants showed their deep trust in God and stated that they put their life in God's hands. Their attitude toward life is to accept what God gives to them, including both the good and the bad in life and not to worry about what they cannot change. (study 1, p. 325, lines 12–15)

I figure if the Lord wanted me to have it, that's what's gonna happen. I just don't worry about it. (study 3, p. 590, lines 3–4)

The second but linked component of this sub-theme relates to the supportive role of spirituality in terms of meaning-making in the presence of dementia. The experience of spirituality appeared to develop usually along with the values and belief systems of the person over the lifespan (studies 4, 7) and brought ultimate meaning to peoples' lives. Living a meaningful life, feeling secure and maintaining identity are connected to the affirmation of the personhood of the person with dementia, as the following demonstrates:

It [spirituality] guides a person's view of the world and self, providing structure, purpose, and meaning to everyday activities. (study 3, p. 589, lines 12–13)

All the participants described an experience of faith that was a living and active part of their lives. This seemed to contribute to their sense of themselves as a person. (study 7, p. 81, lines 2–4)

Certainly, there was evidence of participants turning to spiritual and/or religious beliefs to cope with existential issues. For example the expression of spirituality through faith or developing a faith seemed to help some people with dementia to make sense of their situation (studies 2, 3) and in some instances derive meaning from it, as illustrated here:

I've come to the conclusion that everything has a purpose; the Good Lord knows the best for you. Maybe this was to slow me down to enjoy life and to enjoy my family and to enjoy what's out there. And right now, I can say that I'm a better person for it. (Stuckey et al., 2002, p. 203) (study 2, p. 302, lines 14–20)

The data further suggested that expression of spirituality through faith also served to support personhood (studies 5, 7) and the identity of the person with dementia by linking past to present and related to this was an interesting finding that for some, a re-awakening of interest in the spiritual meaning of life was evident:

...Two people communicated the way in which their faith had been consistent through the spiritual activity of their lives, and that it continued into the present. (study 7, p. 81, lines 8–10)

Some individuals may find a new or renewed interest in seeking out a faith or practice to help them along in this challenging journey . . . Six respondents spoke of ways in which Alzheimer's had influenced their spiritual behaviour or actions. For one Jewish man, this meant a reawakening of his interest in spiritual matters. (study 2, p. 309, lines 12–20)

Overall, this sub-theme illustrates that spirituality for people with dementia may serve as a mechanism for finding hope and making meaning both of which contributed to the affirmation of personhood. Their existing or rekindled reliance on personal spirituality seemed for many to become stronger following diagnosis, and it helped them to find acceptance of their condition and contributed to coping with day to day living.

Sub-theme: Spirituality located and experienced in inter-relationships with others

The experience of spirituality in dementia was found to relate to the way in which it was enmeshed within relationships with others (studies 1–8). Two forms of such relationships were evident, that with a transcendental being (reported in the overarching theme previously) and that with other people (explored here). As such, spirituality while having an intra-personal dimension was equally shown to be socially constructed within the spaces and places between and among others:

I'm a spiritual person who lives it and reflects in what you do ... [Spiritual care is] to help everybody I can ... and teach and talk to and love (Larry person with dementia). (study 5, p. 405, lines 11–13)

All of the participants spoke of ways in which their connections with others helped them to express their spirituality or to feel connected spiritually. (study 7, p. 89, lines 40–41)

Spirituality was referred to as embodied through connection and for many expressed through religiosity (studies 2, 3, 4, 7), while simultaneously acting as a means to connecting with others. This is an important consideration as research exploring the experience of the condition of dementia has often constructed the experience as resulting in a withdrawal by the person with dementia from others or others withdrawing from the person as the condition advances. However, spirituality, in many of the studies reviewed here was characterised as a means to ongoing connection when other forms of social relationships became more difficult to sustain. One of the primary ways in which spirituality existed in inter-relationships with others was manifested in the act of, and importance to the person of, maintaining a connection to one's faith community, particularly where a person had an active and in some cases leadership role within this community. Where a sense of belonging or connection to a faith community was present, participants often referred to the meaningful role that they played in that community. Thus, the lived experience of spirituality provided a sense of continued occupation and was manifested in terms of the self being active in relation to others:

Eight participants continue to serve in a church role such as deacon, choir member of usher ... These activities fulfill their needs to be useful and give them a sense of accomplishment ... 'When [people at church] they got questions, they call on me for support'. (study 3, p. 591, lines 24–27)

However, there were some reports of the ways in which dementia could negatively impact on engagement with others in terms of sustaining or expressing spirituality:

... Alma seemed to be communicating a sense in which she felt less of a person in the social world. (study 7, p. 83–84, line 42.1)

Where this occurred, findings indicated that this was an issue particularly where cognitive decline was advancing (studies 2, 7). In response, some of the study participants described how they adapted to and/or relied on others for facilitation of continued spiritual involvement including: transport to and from spiritual meeting places or the substitution of a particular geographic pre-dementia faith community with a new and more accessible one, for example located within a residential setting. Where physical engagement with a faith community was challenging or anticipated to become so, there was an open acknowledgement that support or enablement of personal spirituality (now or into the future) was, or might be, reliant on others for its continuance (studies 2, 7, 8). This was another way in which spirituality could be located, experienced and supported in inter-relationship with others even in the presence of living with the impacts of advancing dementia:

As my journey into Alzheimer's progresses, my walk with the Lord grows more precious. I am frightened that the day will come when I no longer will be able to think of God's everlasting promises. Then I will have to rely on my dear friends in Christ to keep me close to our Lord . . . (study 2, p. 308, lines 30–38)

My daughter is my salvation . . . She is my strength . . . I know the Lord is involved, and I think he sent her here. She moved there to be with me. That is sacred. (study 8, p. 235, lines 33–38)

Overall, this sub-theme illustrates that the lived experience of spirituality in dementia can be embodied within interconnections with others. This was shown to be a two way process, the balance of which tended to vary in individual cases and over the trajectory of the condition. As such, in the earlier phases of dementia, the person with dementia leads out, while potentially in the more advanced phases others become more active in enabling the person with dementia to uphold and express their personal spirituality in ways meaningful to the individual.

Sub-theme: Spirituality-related practices enacted in everyday living

The final sub-theme illuminates the way in which the embodied experience of spirituality for persons with dementia was referred to in terms of being enacted in the context of everyday living. While related to, this differs to spirituality being experienced in inter-relation with others as it relates to personal spirituality practices and beliefs that generally continued to be integrated into daily life (studies 1–8):

All the participants described an experience of faith that was a living and active part of their lives. (study 7, p. 81, lines 2)

The nature of the faith practices engaged in were varied with one study (study 1) outlining that both private and public religious practices were common among participants. For example attending church, or accessing services via radio or television (studies 1, 2) were shown to offer familiarity and a reassurance that gave participants strength. Personal expressions of spirituality were also common through prayer and music and there was some suggestion that such activities could mediate memory loss:

Reading, reciting, or hearing certain Bible verses was reassuring and comforting for all participants. (study 3, p. 590, lines 27–28 and p. 591, lines 1–3)

To the extent that singing religious hymns was related to the practice of worship, several participants reported private and corporate involvement in this activity. One narrative reflected the meaningfulness of this practice for dealing with memory loss. (study 8, p. 240, lines 17–20)

There were also examples of the enactment of spirituality through non-religious means:

For some individuals, the idea of being spiritual but not religious is a matter of finding personal fulfilment in aspects of human life with which they connect at an intangible, emotional level that is both satisfying and meaningful. The worlds of art and music, the wonders of nature, holiday celebrations and the bonds of social relationships are examples of other expressions of spirituality that eclectically draw meaning – such as peace, wonder, joy, or love – from many different sources. (study 6, p. 68, lines 42–43 and p. 68, lines 1–5).

The use of spiritual symbols/instruments and rituals (studies 2, 3, 7) were further referred to in terms of the practice of spirituality, for example:

Observations of the participants' homes revealed symbols of their relationships or religious artifacts such as crucifixes, crosses, angels, framed pictures with Bible Scriptures, and church hymnals. (study 3, p. 590, lines 12–14)

Inevitably however, for some people the practice of spirituality in daily life became challenging as dementia advanced. In such instances, participants mourned this as a significant loss:

Well, I don't get to go to church, I don't. I'd have to ask them [children] to take me to church I miss that (study 1, p. 327, lines 26–28)

A Catholic man found that his religious practice was being dramatically altered by the effects of Alzheimer's disease. He wrote: I no longer remember prayers I once recited automatically. The prayers frequently get mixed up with each other As for the sacrament of penance or confession it too requires memory. (study 2, p. 307, lines 33–40)

As such, a dependence on more private forms of spiritual practice (and others to facilitate spiritual expression, as shown previously) grew enabling spirituality to continue to be a source of strength:

Persons with early-stage dementia experience cognitive changes that limit their independent religious activities. Therefore, their religious practice becomes more private than public. A personal relationship with God, mostly through prayer, seems to be very important to them. (study 1, p. 326, lines 13–16)

Overall, this sub-theme demonstrates that for many people living with dementia, engagement with faith practices appears to facilitate integration, enjoyment and the expression of spirituality. In such instances, familiar spiritual or religious rituals were found to be reassuring and a means to experience contentment. However, where this was experienced as challenging there was a sense of loss. This was for various reasons depending on the circumstances and individual's personal experience of the impact of dementia but reasons included an inability to attend services and memory problems that for some impacted on the enactment of spirituality related activities.

Discussion

Good dementia care embraces a respect for the person's 'life story'. Such an approach to care takes cognisance of the life history of the person and how s/he has lived life up until now (Caspari et al., 2014). Furthermore, it facilitates meaningful engagement between carers and the person living with dementia (Caspari et al., 2014). It is important while caring for people with dementia and getting to know the person, their family and the emerging life story, that a sense of the person's underlying spiritual and religious beliefs are determined (Caspari et al., 2014). It is often perceived, due to the secular nature of society, that people are less religious or spiritual now than in previous generations (Paley, 2008). Indeed some carers may have discomfort with addressing this element of people's lives, and it is often a low priority in care settings (Powers & Watson, 2011). However, the spiritual is widely accepted as another component of the holistic person. It is also understood that spirituality and religion may become more important for people as they age (Atchley, 2003), and that contemplation of life's meaning and purpose is increasingly common during the aging process and towards the end of life (MacKinlay, 2012).

One important element emerging from this study is the coming together of what is known about the phenomenon which results in new understanding of the experience of spirituality for those with dementia. For many, spirituality took on a personal meaning that was closely intertwined with their sense of the self. Indeed there was evidence that spiritual behaviours and spiritual needs may be heightened in the presence of dementia. It is important, however, when seeking to address these needs in practice, that this is done on an individual needs led basis and not based on assumptions (McSherry, 2006). Personal needs vary, and for some clients, spiritual and religious beliefs may not be important (Molzahn et al., 2012), therefore a blanket approach to providing spiritual support to groups of people should be avoided. Those with dementia are particularly vulnerable as they may not be able to express their preferences in advanced dementia, so close liaison with family members (Powers & Watson, 2011), and careful recording of life histories will make their needs more accessible. At the same time, it must not be assumed simply because there is cognitive decline that there are no spiritual and religious needs present (Powers & Watson, 2011).

Religion, religiosity, transcendence or a connection/relationship with a transcendental being or God were sources of strength emerging from this review. Related beliefs assisted people to accept their diagnosis and live more easily with dementia. Religious rituals have been identified as comforting for people (MacKinlay, 2012; Timmins, Kelly, Threadgold, O'Sullivan, & Flanagan, 2015) and staff have noted that saying of prayers, singing hymns and use of quiet sacred space can reduce distress in those living with dementia (Ødbehr, Kvigne, Hauge, & Danbolt, 2014). Again linked care approaches need to be individualised, but staff ought not to be discouraged from supporting clients' particular religious needs where appropriate. Professional carers may lack knowledge and awareness in this regard, and therefore, it is important to use available resources to assist with this. The Royal College of Nursing (RCN, 2015), for example provides a useful resource and a guide to assessing clients' spiritual needs in practice (RCN, 2011). Chaplaincy services are also very useful support services as they are specifically prepared to directly assess and address clients' spiritual needs (Fitchett & Nolan, 2015). Within the literature it is recognised that the spiritual care of a person with dementia can be overlooked particularly when the person can no longer ask for such support. It is important therefore to raise awareness of the continuation of spiritual needs despite cognitive decline, and the potential benefit of

addressing those needs. It is also important to remember the importance of religious rituals at the end of life, particularly as dementia is a life limiting condition (Peacock, Duggleby, & Koop, 2014). This is furthermore important as the facilitation of spiritual and/or religious rituals around death can also be incredibly supportive for families (Newell & Carey, 2008; Nuzum, Meaney, & O'Donoghue, 2014).

The finding that spirituality is enmeshed in inter-relationships with others is consistent with the work of Nagai-Jacobsen and Burkhardt (1989) who identified one of the characteristics of spirituality as a sense of harmonious interconnection with others as well as self and an ultimate other. These writers also understand spirituality as a factor which serves to integrate the human person, and that the experience of spirituality for the person living with dementia contributes to the upholding of personhood. Of particular importance in this review was the finding that a person's engagement with their own spirituality was further shown to enable confirmation of oneself and a recognition and confirmation of the person by others, and a means to aim for, if not attain, transcendence. Seeking to assess clients spiritual needs and providing support for these (RCN, 2011, 2015), including sacred space (MacKinlay, 2012), may enable people living with dementia to maintain and develop their relationship with the transcendent. Supporting and nurturing relationships with family is also important, as is the acknowledgment, within the understanding of the person's life story, of the importance of these people in their lives. Wheeler's (2010, p. 19) interviews with 36 staff caring for older people with dementia for example found that nurses felt that it was important to engage with clients completing their tasks and nursing care. It was helpful if this involved 'reminiscence' and 'involving family and keeping family on board'. These actions built relationships and opened communication. Engagement and building of relationships between both client and family and client and staff are also essential components of person-centred (Brooker & Latham, 2015) and relationship-centred (Brown-Wilson, 2013) care. It is observed that clients may become dehumanised and objectified in healthcare settings, whereby tasks are the main focus rather than the person (Clarke, 2013). Seeking to engage with the spiritual, that is what the client finds meaningful in life, serves to restore personhood (Clarke, 2013), and certainly from this review, and as advocated by Duggleby et al. (2012), helps renew a sense of hope.

People with dementia considered their spirituality as part of their everyday living. This finding demonstrates the value and importance of spiritual practices and beliefs in the daily life of those living with the condition and supports the growing concern about the need to address clients' spiritual needs (Cullen, 2016). Only by understanding what gives life meaning, and what those individual spiritual needs are, can effective support be provided to each person (RCN, 2015). At the same time, it is important to remember that spiritual support needs to be individualized. As such assumptions must not be made that all people living with dementia will require spiritual support. Rather this will be dependent on their life story and particular preferences, much of which can be determined from an accurate life history assessment and from speaking with friends and family. However at the same time, the review findings certainly indicate that this is an important facet of life for many living with dementia. Facilities that are often incorporated into nursing home and other such care settings, such as sacred space, religious rituals and chaplaincy support (MacKinlay, 2012), ought to be encouraged and developed to support the needs of the community. Where clients are not from the majority religious faith, and have expressed religious needs, referrals may be made by the staff or chaplains to community religious groups (Health Service Executive, 2011; Swift, 2015) so that clients may receive support in this way. In the studies reviewed,

many participants felt disappointed that their advancing dementia was experienced in a way that meant that they were challenged to, or could no longer, participate in local community religious occasions and events. For these people, the findings suggest that establishing a parallel situation in residential care, could be very important in re-establishing meaning and connection, and providing support and hope with a challenging diagnosis and the related impacts on a person's life journey. Overall, it is important to:

... acknowledge the spiritual dimension of a person and support spiritual expression and growth. Spirituality no longer merely denotes religious affiliation, it synthesizes a person's contemplative experience. Illness, a life crisis, or even the recognition that our days on earth are limited may cause a person to contemplate [their] spirituality. (Meiner, 2010, p. 25)

Limitations

Only studies written in the English language were included in this review due to a lack of access to translation services. In addition, the writers while attempting to capture all related literature acknowledge the difficulty in ensuring an exhaustive literature search when conducting a meta-synthesis – e.g. variety of research approaches and the underlying focus of the primary research itself. Therefore, the possibility exists that other relevant studies and studies in languages other than English may exist.

Conclusion

This meta-synthesis explored the experiences of spirituality from the perspective of the person living with dementia that have been reported in peer reviewed published literature. Our intent was to create a synthesised interpretation from the existing evidence base so as to advance understanding of the phenomenon. Overall the studies included indicated that people with dementia experience a deep understanding of spirituality, often enhanced by their remembrance of early life experiences. Faith, belief and rituals over the life-course were shown to sustain the person through the challenges they encounter in living with dementia. The potential benefits of faith rituals have been identified in other studies (Timmins et al., 2015). Embracing spirituality, which is unique to each person, creates the potential for individuals, adapting to and living with the life changing events that accompany a diagnosis of dementia. As such, spirituality was shown as a means, to cope with and ascribe meaning to these events. Spirituality may also be experienced through connection with others, and the importance placed on this, whether it be family or faith community, serves to energise at least some people with dementia who reported that living with their diagnosis was made easier by having a belief and faith. Increasingly, in this secular age it is common to overlook the potential spiritual needs of clients receiving healthcare (Radford, 2008). The findings of this systematic review affirm the importance of not neglecting the importance of spirituality and spiritual needs of those living with dementia. They further confirm the need for spiritual competence for health and social care practitioners involved in dementia care.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

References

- Atchley, R. (2003). *The continuity of the spiritual self in aging, spirituality and religion: A handbook* (Vol. 1). Minneapolis, MN: Fortress Press.
- Bell, V., & Troxel, D. (2001). Spirituality and the person with dementia – A view from the field. *Alzheimer Care Quarterly*, 2, 31–45.
- Bettany-Saltikov, J. (2012). *How to do a systematic literature review in nursing. A step by step guide*. Maidenhead, UK: Open University Press.
- Beuscher, L., & Grando, V. T. (2009). Using spirituality to cope with early-stage Alzheimer's disease. *Western Journal of Nursing Research*, 31, 583–598.
- Booth, A., Papaioannou, D., & Sutton, A. (2012). *Systematic approaches to a successful literature review*. London, UK: Sage.
- Brillhart, B. (2005). A study of spirituality and life satisfaction among persons with spinal cord injury. *Rehabilitation Nursing*, 30, 31–34.
- Brooker, D., & Latham, I. (2015). *Person-centred dementia care*. London, UK: Jessica Kingsley.
- Brown-Wilson, C. (2013). *Caring for older people, a shared approach*. London, UK: Sage Publishin.
- Caldeira, S., Carvalho, E., & Vieira, M. (2013). Spiritual distress – proposing a new definition and defining characteristics. *International Journal of Nursing Knowledge*, 24, 77–84.
- Campbell, R., Pound, P., Pope, C., Britten, N., Pill, R., Morgan, M., & Donovan, J. (2003). Evaluating meta-ethnography: A synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social Science and Medicine*, 56, 671–684.
- Carr, T. J., Hicks-Moore, S., & Montgomery, P. (2011). What's so big about the little things? A phenomenological inquiry into the meaning of spiritual care. *Dementia*, 10, 399–414.
- Carroll, M., & Shaw, E. (2013). *Ethical maturity in the helping professions*. London, UK: Jessica Kingsley.
- Caspari, S., Lohne, V., Wilhelm Rehnfeldt, A., Sæteren, B., Slettebø, A., Kari Tolo Heggstad, A., ... Nåden, D. (2014). Dignity and existential concerns among nursing homes residents from the perspective of their relatives. *Clinical Nursing Studies*, 2, 22–33.
- Clarke, J. (2013). *Spiritual care in everyday nursing practice. A new approach*. Basingstoke, UK: Palgrave Macmillan.
- Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO: The SPIDER tool for qualitative evidence synthesis. *Qualitative Health Research*, 22, 1435–1443.
- Cullen, J. (2016). Nursing management, religion and spirituality: A bibliometric review, a research agenda and implications for practice. *Journal of Nursing Management*, 24, 291–299.
- Dalby, P., Sperlinger, D. J., & Boddington, S. (2012). The lived experience of spirituality in older people living with mild to moderate dementia. *Dementia*, 11, 75–94.
- Daly, L., & Fahey-McCarthy, E. (2014). Attending to the spiritual in dementia care nursing. *British Journal of Nursing*, 23, 787–791.
- Duggleby, W., Hicks, D., Nekolaichuk, C., Holtslander, L., Williams, A., Chambers, T., & Eby, J. (2012). Hope, older adults, and chronic illness: A metasynthesis of qualitative research. *Journal of Advanced Nursing*, 68, 1211–1223.
- Eliopoulos, C. (2014). *Gerontological nursing* (8th ed). Philadelphia, PA: Wolters Kluwer Health/ Lippincott Williams and Wilkins.
- Fitchett, G., & Nolan, S. (Eds.) (2015). *Spiritual care in practice. Case studies in healthcare chaplaincy*. London: Jessica Kingsley.

- Frankl, V. E. (1963). *Man's search for meaning*. New York, NY: Washington Square Press, Simon and Schuster.
- Handoll, H. H. G., & Smith, A. F. (2004). How to perform a systematic review. *Current Anaesthesia & Critical Care*, *14*, 251–257.
- Hannes, K., & Lockwood, C. (2011). Pragmatism as the philosophical foundation for the Joanna Briggs meta-aggregative approach to qualitative evidence synthesis. *Journal of Advanced Nursing*, *67*, 1632–1642.
- Health Service Executive. (2011). *A question of faith: The relevance of faith and spirituality in health care*. Dublin: Health Service Executive. Retrieved November 13, 2015 from http://www.hse.ie/eng/services/publications/corporate/Your_Service_Your_Say_Consumer_Affairs/Reports/questionoffaith.pdf
- Katsuno, T. (2003). Personal spirituality of persons with early-stage dementia. Is it related to perceived quality of life? *Dementia*, *2*, 315–335.
- Khan, K. S., Kunz, R., Kleijnen, J., & Antes, G. (2003). Five steps to conducting a systematic review. *Journal of the Royal Society of Medicine*, *96*, 118–121.
- Korhonen, A., Hakulinen-Vitanen, T., Jylhä, V., & Holopainen, A. (2013). Meta-synthesis and evidence-based health care – A method for systematic review. *Scandinavian Journal of Caring Sciences*, *27*, 1027–1034.
- Lundgren, I., Begley, C., Gross, M. M., & Bondas, T. (2012). 'Groping through the fog': A metasynthesis of women's experiences on VBAC (Vaginal birth after Caesarean section). *BMS Pregnancy and Childbirth*, *12*. Retrieved from <http://brage.bibsys.no/xmlui/bitstream/handle/11250/286465/Bondas.pdf?sequence=3&isAllowed=y>
- MacKinlay, E. (2006). *Spiritual growth and care in the fourth age of life*. London: Jessica Kingsley.
- MacKinlay, E. (2009). Using spiritual reminiscence with a small group of Latvian residents with dementia in a nursing home: A multifaith and multicultural perspective. *Journal of Religion, Spirituality & Aging*, *21*, 318–329.
- MacKinlay, E. (2012). *Palliative care, aging and spirituality. A guide for older people, carers and families*. London: Jessica Kingsley.
- MacKinley, E. B., & Trevitt, C. (2006). *Facilitating spiritual reminiscence for older people with dementia: A learning package*. Canberra, Australia: CAPS Publishing.
- McGee, J. S., Myers, D. R., Carlson, H., Funai, A. P., & Barclay, P. A. (2013). Spirituality, faith, and mild Alzheimer's disease. *Research in the Social Scientific Study of Religion*, *24*, 221–257.
- 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.
- 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, UK: Oxford University Press.
- Meiner, S. E. (2010). *Gerontologic nursing* (4th ed). St. Louis, MO: Mosby.
- Molzahn, A., Shields, L., Bruce, A., Stajduhar, K., Makaroff, K. S., Beuthin, R., & Shermak, S. (2012). People living with serious illness: Stories of spirituality. *Journal of Clinical Nursing*, *21*, 2347–2356.
- Nagai-Jacobson, M. G., & Burkhardt, M. A. (1989). Spirituality: Cornerstone of holistic nursing practice. *Holistic Nursing Practice*, *3*, 18–26.
- Narayanamy, A. (2010). Recognising spiritual needs. In W. McSherry, & L. Ross (Eds.), *Spiritual assessment in healthcare practice* (pp. 37–55). Keswick: M&K Publishing.
- Newell, C., & Carey, L. B. (2000). Economic rationalism and the cost efficiency of hospital chaplaincy: An Australian study. *Journal of Health Care Chaplaincy*, *10*, 37–52.
- Noblit, G. W., & Hare, R. D. (1988). *Meta ethnography: Synthesizing qualitative studies*. London, UK: Sage.
- Nuzum, D., Meaney, S., & O'Donoghue, K. (2014). The provision of spiritual and pastoral care following stillbirth in Ireland: A mixed methods study. *BMJ Supportive and Palliative Care*, 1–7. Retrieved from <http://spcare.bmj.com/content/early/2014/06/10/bmjspcare-2013-000533.abstract>
- Ødbehr, L., 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.

- Paley, J. (2008). Spirituality and secularization: Nursing and the sociology of religion. *Journal of Clinical Nursing*, 17, 175–186.
- Peacock, S., Duggleby, W., & Koop, P. (2014). The lived experience of family caregivers who provided end-of-life care to persons with advanced dementia. *Palliative & Supportive Care*, 12, 117–126.
- Powers, B. A., & Watson, N. M. (2011). Spiritual nurturance and support for nursing home residents with dementia. *Dementia*, 10, 59–80.
- Radford, K. (2008). *Health, faith and equality*. Prepared for the Health Research Board through Building Partnerships for Healthier Society Research Award. Dublin: Health Research Board/Irish School of Ecumenics, Trinity College Dublin.
- Royal College of Nursing. (2011). *RCN spirituality in nursing care: A pocket guide*. London: Author.
- Royal College of Nursing. (2015). *Spirituality in nursing care: Online resource introduction*. Retrieved from http://www.rcn.org.uk/development/practice/spirituality/about_spirituality_in_nursing_care
- Snyder, L. (2003). Satisfactions and challenges in spiritual faith and practice for persons with dementia. *Dementia*, 2, 299–313.
- Swift, C. (2015). *NHS chaplaincy guidelines 2015 promoting excellence in pastoral, spiritual & religious care*. Leeds, UK: NHS England. Retrieved from <http://hcfbg.org.uk/wp-content/uploads/2013/09/nhs-chaplaincy-guidelines-2015.pdf>
- Stuckey, J. C., Post, S. G., Ollerton, S., FallCreek, S. J., & Whitehouse P. J. (2002). Alzheimer's disease, religion, and the ethics of respect for spirituality – A community dialogue. *Alzheimer's Care Quarterly*, 3, 199–207.
- The Joanna Briggs Institute. (2011). *Joanna Briggs Institute Reviewers manual 2011*. University of Adelaide, Australia: The Joanna Briggs Institute. Retrieved from <http://joannabriggs.org/assets/docs/sumari/ReviewersManual-2011.pdf>
- Thorne, S., Jensen, L., Kearney, M. H., Noblit, G., & Sandelowski, M. (2004). Qualitative metasynthesis: Reflections on methodological orientation and ideological agenda. *Qualitative Health Research*, 14, 1342–1365.
- Timmins, F., Kelly, S., Threadgold, M., O' Sullivan, M., & Flanagan, B. (2015). Serenity spirituality sessions: A descriptive qualitative exploration of a Christian resource designed to foster spiritual well-being among older people in nursing homes in Ireland. *Religions*, 6, 299–316.
- Tranfield, D., Denyer, D., & Smart, P. (2003). Towards a methodology for developing evidence-informed management knowledge by means of systematic review. *British Journal of Management*, 14, 207–222.
- Weathers, E., McCarthy, G., & Coffey, A. (2015). Concept analysis of spirituality: An evolutionary approach. *Nursing Forum*. Retrieved from www.ncbi.nlm.nih.gov/pubmed/25644366
- Wheeler, N. L. (2010). Dementia care 1: Person centred approaches help to promote effective communication. *Nursing Times*, 106, 18–21.

Author Biographies

Louise Daly, PhD, MSc, BNS, RNT, RGN is an assistant professor at the School of Nursing and Midwifery, Trinity College Dublin. Her research and education interests include caring for those living with dementia, older person nursing and healthcare ethics. She is a member of the Dementia Services Information and Development Centre Steering Committee and the Ethics Committee of the Nursing and Midwifery Board of Ireland.

Elizabeth Fahey-McCarthy, MA Ed, PhD qualified as a general state registered nurse in 1978 in Ireland. She has held academic posts in Oxford Brookes University (OBU), United Kingdom (1995–1998) and Trinity College Dublin (TCD), Ireland since (2001 to date).

Her research interests include ethics and ethical decision making in health care, reflective practice, palliative and end of life care, loss and grief for staff working with persons with intellectual disability and dementia.

Fiona Timmins, PhD, MSc, MA, FFNRC SI, BNS, BSc, Health & Soc (Open), BA (Open), RNT RGN is as an associate professor at the School of Nursing and Midwifery, Trinity College Dublin. She has more than 106 publications in peer-reviewed journals and has written/co-authored eight nursing textbooks. She has presently at several international conferences including Key Note presentations and workshops. She is a visiting scholar at the Department of Health Sciences, University of Genoa, Italy. Her research interests include professional nursing issues, nurse education, spirituality and reflection.