

Research Article

The Spiritual Experience of Dementia From the Health Care Provider Perspective: Implications for Intervention

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Abstract

Background and Objectives: Spiritual care aims to counter negative outcomes from spiritual distress and is beneficial to persons living with dementia. Such care needs dementia-appropriate customization. We explored the salient spiritual needs in dementia to inform future intervention development. Health care providers are well situated to observe the nature of spiritual needs across and within medical conditions.

Research Design and Methods: We conducted semistructured qualitative interviews with providers. We sampled purposively by discipline (chaplains, nursing staff, social workers, activities professionals) and religious tradition (for chaplains). Our interview guide inquired about, for example, the nature of spiritual needs in dementia and stakeholders' roles in addressing them. Inductive/deductive thematic analysis was employed.

Results: 24 providers participated. The thematic structure consisted of 2 themes: (a) spiritual experience in dementia differs from that in other medical conditions (subthemes: fear, profound loss of self, progressive and incurable nature, and impacted ability to access faith) and (b) the need for spiritual intervention at the mild stage of dementia (subthemes: awareness in mild dementia and its influence on spiritual distress, and a window of opportunity).

Discussion and Implications: We learned about the potential “what” of spiritual needs and “who” and “when” of implementing spiritual care. Implications included the imperative for dementia-specific spiritual assessment tools, interventions targeting fear and loss of self early in symptom progression, and stakeholder training. Researchers should study additionally the “how” of dementia-appropriate spiritual care. Conjointly, these efforts could promote spiritual well-being in persons living with dementia worldwide.

Keywords: Dementia, Qualitative research, Spirituality

Spiritual care seeks to uphold the spiritual well-being of individuals and to address spiritual concerns such as suffering and loss (Puchalski et al., 2019). Within the

health care field, spiritual care's role is fortified by its inclusion in palliative care for those with serious illness (National Consensus Project for Quality Palliative Care,

2018; World Health Organization, 2008). Spiritual care in the health care setting can be provided by chaplains and typically, in more limited ways, by “spiritual generalists” (i.e., non-chaplain providers such as nurses and social workers; Thiel et al., 2020) and can be facilitated in the community by faith-based organizations and family support.

Spiritual care attends to spiritual needs via approaches such as active listening, being present, offering compassion, establishing trusting relationships, and sharing in prayer and meditation and rituals (Jackson et al., 2016). Spiritual needs for adults with serious illness can include the need for a sense of meaning in life and a sense of peace facilitated by extrapersonal connection as well as a sense of faith (Canada et al., 2008; Puchalski et al., 2019). Of note, spiritual and emotional needs can be inextricably linked; for example, hospitalized patients reporting spiritual needs have also expressed the emotions of fear and loneliness related to those needs (Clark et al., 2003).

If spiritual needs in the face of serious illness go unaddressed, negative outcomes may ensue. Individuals may experience spiritual distress, manifesting as the emotions of quotidian sadness and fear to more disabling depression and despair (National Comprehensive Cancer Network, 2003). Spiritual distress in turn can lead to poor mental health, reduced quality of life, and a higher risk of mortality (Pargament et al., 2004). These deleterious outcomes attest to the need for well-developed and tested spiritual care interventions and their inclusion within care models for those living with serious illness (Puchalski et al., 2019). To mitigate spiritual distress in the context of serious illness, studies need to establish an evidence base for how to tailor illness-specific interventions (Beuscher & Beck, 2008; Chen et al., 2018; Puchalski et al., 2019).

Guidance on spiritual care design specific to dementia, a highly prevalent set of serious conditions, is important. Many individuals with dementia could be affected by the negative outcomes of unmet spiritual need; indeed, there are roughly 50 million persons living with dementia in the world, with that number projected to grow threefold by 2050 (World Health Organization, 2019). Furthermore, preventing spiritual distress through intervention holds relevance for those with cognitive impairment, not just for the cognitively intact. Everett (1998) contends that spirituality is not just rooted in cognition but also in emotion, senses, and imagination, all of which are retained in dementia. Bryden (2020), in her autoethnographic account of living with dementia, validates how spirituality may “unlock” persons living with dementia from their cognitive limitations. Further, spirituality has been found to serve as an important resource in coping with dementia as with other serious illnesses. As a coping resource, spirituality can support persons living with dementia in sustaining meaning, purpose, and relationship and in drawing strength from comfort and hope (Agli et al., 2015; Daly et al., 2019; Stuckey & Gwyther, 2003)

Despite spirituality’s importance in the context of dementia, existing research on spiritual care design for individuals with dementia needs more nuance. Ødbehr and colleagues (2017) conducted a metasynthesis of eight qualitative studies on persons’ living with dementia and professional caregivers’ views of spiritual needs in dementia. The authors concluded that there were no notable distinctions across perceptions of spiritual needs for those with cognitive impairment and prior descriptions of spiritual needs for those without cognitive impairment; both groups need faith, connection, and meaning in their lives. The authors surmised that either (a) spiritual needs are largely universal despite the presence of “severe illness and disease” or (b) the studies reviewed did not sufficiently detect particulars of spiritual experience in dementia. More research should answer the following questions that remain: (a) Are there discernible differences in spiritual needs within the category of “severe illness”?, (b) What could such differences teach us about customizing spiritual care?, and (c) Does the spiritual experience in dementia have its own particular phenomenology?

There are additional gaps in the literature regarding spiritual care for dementia. That is, comparisons across varying levels of dementia severity have not been conducted. A conceptual paper from the United Kingdom described means by which nurses can offer spiritual care to those with dementia (e.g., providing human connection, supporting personal practices of religion and faith, and working collaboratively with other disciplines); yet, the paper does not explicitly describe the degree of dementia severity under consideration (Daly & Fahey-McCarthy, 2014). The metasynthesis of qualitative studies mentioned above (Ødbehr et al., 2017) did not distinguish dementia severity in its discussion of spiritual care, and a literature review of exploratory studies in its discussion of spirituality as a coping mechanism focuses specifically on early dementia (Beuscher & Beck, 2008). Since the time these two reviews were conducted, qualitative studies outside the United States have continued to explore spiritual needs and spiritual care in dementia but without clarifying how they may vary by severity of symptomatology. From interviews of persons living with mild dementia, Chen and colleagues (2019) found spiritual needs such as finding meaning in one’s past, establishing control over one’s current life, and bolstering personal strength through faith. In another study, nurses and care workers from various care settings were interviewed about spiritual care practices for persons living with severe dementia (Hirakawa et al., 2020). Participants reported their focus on maintaining care recipients’ self-esteem, employing communication approaches such as active listening and “therapeutic lying,” and honoring care recipients’ individual differences. Burke and colleagues (2018) and Toivonen and colleagues (2018) studied spiritual care for persons living with unspecified severity of dementia. The former study interviewed nursing home staff; staff described the value of supporting the spirituality of

residents living with dementia via strong organizational backing, relational care, making the issue “everybody’s business,” and focusing on the residents’ growth and flourishing. The latter study, based on interviews with nurses from various care settings, found staff relied on verbal and nonverbal communication and knowledge of care recipients’ spiritual background to discern spiritual needs. These findings offer initial insights into spiritual care for dementia; however, the research base still needs to demonstrate conceptual clarity about dementia severity or, when it does make the conceptual distinction, needs to identify whether or not findings are transferable from one level of dementia severity to another. Thus, there is another important research gap: We cannot discern whether or not spiritual experience is equivalent across varying levels of dementia severity; without this knowledge, we cannot optimally tailor spiritual care for the dementia context.

Our aim herein is to redress these research gaps to ultimately inform spiritual intervention design. We conducted a qualitative pilot study, interviewing persons living with dementia as well as health care providers who work with older adults, inclusive of persons living with dementia. This paper focuses on the interviews with health care providers to address the following research question: What are the salient spiritual needs in persons living with dementia? We chose to interview these providers given their in-depth and targeted clinical experience with dementia and other serious illnesses. Providers’ clinical experience may offer well-grounded insight into the spiritual experiences of persons living with dementia and hands-on appreciation of how these spiritual experiences vary within dementia as well as across dementia and other medical conditions.

Method

Overview

Both Hebrew SeniorLife’s Institutional Review Board (IRB; the IRB of record during data collection and data coding) and VA Boston Healthcare System’s IRB (the IRB of record during subsequent analysis of de-identified data) ruled this qualitative study protocol to be of minimal risk and thus exempt from further IRB review. The latter organization’s Research and Development Committee, however, maintained oversight of the protocol.

Setting and Participants

Interview participants were health care providers recruited from a variety of community-based (e.g., adult day center, outpatient memory care clinic, independent housing) and long-term care (e.g., assisted living facility, continuing care retirement community) settings in the Greater Boston area. Participants were eligible for the study if they worked directly with persons living with dementia and were eligible

even if they did not report having a spiritual or religious affiliation.

We purposively sampled participants by profession, focusing on professions (i.e., chaplains, nursing staff, social workers, activities professionals) most likely to encounter spiritual issues among their direct care recipients. For chaplain participants, we also purposively sampled by faith (i.e., Judaism, Protestantism, Catholicism). Recruitment included the following approaches: points of contact were established at each site and provided work e-mail addresses of potential participants to the research team and arranged for the first author (J. A. Palmer) to introduce the study at staff meetings as needed.

Data Collection

The first author (J. A. Palmer), an experienced doctoral-level health services researcher, conducted this study’s semistructured qualitative interviews over a 4.5-month period (April to September, 2019). All interviews but one occurred in-person in a private location chosen by the participant. The exception was an interview held over the telephone. Mean interview duration was 40 min (range: 22–59 min).

Interview sessions began with participants completing a brief demographics form. Subsequent semistructured interview questions explored topics in the context of dementia including (a) the nature of spiritual needs, (b) barriers and facilitators to meeting those needs, (c) family members’ and friends’ role in helping to meet those needs, and (d) providers’ role in and associated preparation for helping to meet those needs (see [Supplementary Material](#) for interview guide). The study’s initial intent was to ask questions about spiritual needs only in the mild stage of dementia, though the fluid nature of the semistructured format led to discussion of spirituality in all stages of dementia more generally as well. Interview question development relied on a definition of three spirituality constructs (i.e., faith, peace, meaning) established in the development of the Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale, a validated measure to assess spiritual well-being in persons with chronic illness ([Canada et al., 2008](#)). Participants were initially asked to respond to questions about “spiritual needs” in dementia according to their own implicit definition; the interviewer (J. A. Palmer) followed up with explicit examples of spiritual needs with probe questions as needed. All interviews were digitally recorded and professionally transcribed verbatim.

Data Analysis

We conducted thematic analysis of the qualitative data, selecting this approach based upon its (a) ease in use (given the pilot study’s resource constraints), (b) capacity to underscore both similar and different findings across the data,

and (c) utility for practical applications (Braun & Clarke, 2006). Codes and themes were identified both inductively (as they emerged from the raw data) and deductively (derived from domains in the interview guide).

Two researchers (J. A. Palmer and a trained research assistant with a Master's degree) familiarized themselves with the data by fully reading all transcripts. These two researchers independently reread the same five transcripts as one another, each researcher creating her own list of inductively and deductively derived codes. J. A. Palmer compared the two lists, condensing and redacting codes as needed to ensure the codes were comprehensive yet conceptually distinct. Using the refined list of codes, J. A. Palmer drafted a structured codebook that delineated the name, definition, and relevant inclusion and exclusion criteria for each code (DeCuir-Gunby et al., 2011). The research assistant reviewed and approved the refined list of codes and the drafted codebook before their application.

Using the codebook, the coders independently coded data while holding weekly consensus meetings to resolve coding discrepancies. Examples of initial codes consisted of "acceptance or denial regarding illness," "spiritual state of being changed depends on the individual," "spiritual struggle or distress related to fear or anxiety or stress," and "spiritual well-being related to sense of identity being intact." The codebook evolved as analysis progressed; for example, instances of reported "discomfort" of persons living with dementia regarding illness emerged as a code later in the coding process. When the codebook was updated, we recursively recoded previously coded transcripts with newly discovered codes (such as, the new code of presence or absence of "discomfort regarding illness"). In this manner, we intended and ensured that instances of newly discovered codes were captured in all transcripts. To pursue methodological rigor, both positive and negative cases of each code were coded; for example, we coded "fear or anxiety or stress" both when participants stated such distress was present among persons living with dementia and when participants had not observed that type of distress.

The first author (J. A. Palmer), guided by our research question, identified possible themes and subthemes by using tables; these tables organized codes and facilitated collation of data extracts associated with the codes. During this process, the researcher was able to visualize conceptual relationships within the codes and within the themes and their subthemes. J. A. Palmer and another doctoral-level researcher (M. Hilgeman) next independently reviewed the tables to verify internal cohesion within and external distinctiveness across themes. After review, J. A. Palmer and M. Hilgeman independently defined and named themes and their subthemes, grounding these preliminary decisions in the data. Consensus meetings were then held to assess the thematic structure established by each researcher. The senior author (J.L. Sullivan), an experienced qualitative researcher with a doctorate in Gerontology, attended the meetings and arbitrated any discrepancies. In a final step,

J. A. Palmer also reviewed the data to explore differential patterns of findings by provider type and by religious/spiritual affiliation. NVivo 12 software and Microsoft Excel 2013 spreadsheets were used throughout analysis to manage and manipulate the data.

Results

Twenty-four providers (10 chaplains, six nursing staff members, six social workers, and two activities professionals) participated in interviews. All participants were Caucasian, and the majority were female, had graduate degrees, worked in long-term care settings, and had worked in their profession for more than 20 years. Data confirm that 23 of the providers had experience serving both older adults with dementia and those with other medical illnesses; data on this variable are missing for the remaining provider. The chaplains, as purposively selected, personally identified with a range of Jewish and Christian faith traditions (Jewish: $N = 4$; Protestant: $N = 4$; Catholic: $N = 2$; see Table 1 for full details on participant demographics.)

We identified two themes, discerning no differential patterns in findings by provider type or by religious/spiritual affiliation. Theme 1 related to how spiritual experience in dementia differs from that in other medical conditions. This theme's four subthemes were (1a) fear in dementia, (1b) profound loss of self in dementia, (1c) progressive and incurable nature of dementia, and (1d) impacted ability to access faith in dementia. Theme 2, the need for spiritual intervention at the mild stage of dementia, had two subthemes: (2a) awareness in mild dementia and its influence on spiritual distress and (2b) a window of opportunity. We describe each theme with its subordinate subthemes below, highlighting nuance where subthemes have partial conceptual overlap with each other. Table 2 provides exemplary participant quotes which support the thematic structure.

Theme 1: Spiritual Experience in Dementia Differs From That in Other Medical Conditions

The majority of participants considered the salient challenges to meeting spiritual needs in dementia as distinct from those in a variety of other conditions. The spiritual needs mentioned by participants included those prompted by the interview guide's core constructs of spirituality (e.g., faith and peace) and those raised by participants themselves or emergent in response to additional probe questions (e.g., identity and hope). Findings underscored the spiritual needs particularly salient within the dementia experience: (a) the fear in dementia (subtheme 1a) can disrupt a sense of peace, (b) the profound loss of self in dementia (subtheme 1b) can disrupt a sense of identity, (c) the progressive and incurable nature of dementia (subtheme 1c) can disrupt a sense of peace and hope, and (d) impacted

Table 1. Staff Characteristics (*N* = 24)

Characteristic	<i>N</i>
Age	
30–39	4
40–49	4
50–59	7
60+	8
Gender	
Female	20
Male	4
Race	
White	24
Ethnicity	
Neither Hispanic nor Latino/a	21
Hispanic or Latino/a	1
Unknown or not reported	2
Profession	
Chaplaincy	10
Nursing	6
Social work	6
Activities professionals	2
Work setting	
Community-based	9
Long-term care	15
Highest level of education	
Some college or bachelor's degree	5
Graduate degree	19
Years in profession	
1–4	5
5–9	5
10–19	4
20+	10
Religious/spiritual affiliation	
Affiliated with a religion	
Jewish	6
Catholic	4
Protestant	6
Spiritual but not religious	6
Not spiritual nor religious	2

ability to access faith in dementia (subtheme 1d) can disrupt spiritual connectedness.

There were a few instances of contradictory findings to theme 1, however. One participant suggested that spiritual needs varied across persons as individuals. Four participants stated that they did not know of or had not witnessed any spiritual needs among individuals living with dementia.

Subtheme 1a: fear in dementia

Many participants described dementia as a set of conditions that invoke the spiritual challenge of fear more so than some other conditions. Fear may represent an obstacle to the spiritual need of peace. One participant stated this perspective describing dementia as “much scarier” compared to two other chronic conditions (i.e., diabetes and heart

failure). Several participants expounded upon this straightforward description of dementia as frightening. A participant highlighted how loss of one’s own “mind” contributes to individuals’ fear. Another participant expanded upon this point further. S/he noted how dementia’s loss of self (a subtheme elaborated upon in subtheme 1b), in contrast to a condition like pancreatic cancer, leads to persons living with dementia who are aware of their condition being “terrified.”

Indeed, our participants alluded to dementia-induced loss of self as causing fear in those affected, a particularly notable impact compared to other medical conditions. While this subtheme focuses on fear (which can be due to loss of self) as a salient source of spiritual distress in dementia, the subtheme below focuses on the inverse: loss of self (which can be frightening) as a salient source of spiritual distress in dementia.

Subtheme 1b: profound loss of self in dementia

Several participants emphasized how identity is a spiritual need and how salient the spiritual impact of loss of self in dementia is, making it stand apart from other conditions. A participant shared their view on how this loss of self is “unique” in dementia-related illness (including Parkinson’s disease); such illness leaves the affected individual anticipatorily questioning their sense of self. Additional participants advanced this point further. One participant stated how the loss of cognitive processing abilities and of prior long-held sense of identity in dementia leads to a highly different illness experience than in some other conditions (i.e., mobility impairment, renal failure). One participant continued in this vein by underscoring how loss of self is one of the “primary” spiritual issues in dementia. The participant further opined that physical diseases do not compare to dementia in terms of the latter’s deep spiritual crisis associated with its profound “threat to self.”

Subtheme 1c: progressive and incurable nature of dementia

Several participants mentioned the terminal nature of dementia as a salient feature compared to a number of other conditions, that is, nonterminal ones. This terminal nature can threaten the spiritual needs of peace and of hope. A participant shared how spiritual concern arises with dementia versus nonterminal disease related to issues of acceptance or “reckoning.” Another participant highlighted how the ultimately untreatable nature of dementia leads to significant “loss of control” compared to conditions for which corrective technologies (i.e., knee replacement surgery, coronary artery bypass grafting) exist. Here again, the issue of loss of agency innate to dementia surfaces, in this case due to dementia’s inevitable progression. Comparing dementia to traumatic brain injury, another condition associated with cognitive impairment, an additional participant pointed to how

Table 2. Exemplary Participant Quotes Supporting the Thematic Structure

Subtheme	Participant quotes
Theme 1: Spiritual experience in dementia differs from that in other medical conditions	
1a. Fear in dementia	<p>“...they [persons living with dementia] can expect at some point down the road to lose the ability to speak, to recognize loved ones, to independently care for themselves ... it’s rightfully called a thousand little goodbyes—you say goodbye to many different parts of yourself ... so I think unique to dementia is being able to kind of look down the road—like it’s hazy—and knowing that those signposts are going to come—but having no idea when they’re going to appear ... that’s scary; that’s terrifying.” [Participant 14]</p> <p>“Okay, back to what’s unique about the dementia. I think just the fear and anxiety of the changes and losing grasp and losing your mind, literally ...” [Participant 15]</p> <p>“But even if they die [patients with pancreatic cancer], they don’t think they’ll lose control of who they are. They’ll get sick. They’ll die. But they’ll still be who they are. And people who get a diagnosis of dementia and understand what that is are terrified. It’s the worst thing that can happen.” [Participant 7]</p>
1b. Profound loss of self in dementia	<p>“...the loss of self—the loss of selfhood is unique to dementia or similar diseases like Parkinson’s ... you know that when that time comes you’re not going to be who you are today, you’re not going to have the mind and the self that’s available to you in this moment ...” [Participant 14]</p> <p>“...even if you’re wheelchair bound or you need to use a walker and you got to go to dialysis every day or something like that, it’s so different from losing your cognition and your ability to process and be who you’ve always identified yourself as.” [Participant 13]</p> <p>“This threat to self is so primary with dementia that I think it has a very different impact, spiritually ... And the fear is that with increased dementia one’s sense of self will dissolve. And one won’t be oneself. And so the existential nature of that threat is huge. ... I don’t think they [physical diseases] do as deep a wound to self—as deep a relational wound as dementia does.” [Participant 8]</p>
1c. Progressive and incurable nature of dementia	<p>“I think the difference is the reckoning with this thing that won’t ever go away versus a thing that may possibly be treatable and go away.” [Participant 13]</p> <p>“...there’s really no way to fix it [dementia] ... in technology, there’s—we have things that we can—we can have a new heart. We can have a new—we can have a bypass. We can have our knees replaced ... but we really can’t do anything about our [cognition] ... So, that loss of control on that side is phenomenal.” [Participant 18]</p> <p>“So dementia is a progressive thing, and it is giving up—giving up. Traumatic brain injury is living with the drastic neurological changes. Sometimes they’re progressive, like dementia, but a lot of it is trying to regain—trying to redefine ‘who am I’ after this incident. There’s some of that in dementia, but it’s a continual loss. It’s grieving ...” [Participant 24]</p>
1d. Impacted ability to access faith in dementia	<p>“If you have dementia ... you might be able to have that insight, that perspective, like ‘Somehow I have to get through this, I can pray, I can get support from my family, maybe if I take some Aricept.’ ... I think it’s much, much—much, much harder if you’re in—if you have a diagnosis of dementia—to kind of get support.” [Participant 23]</p> <p>“Well, in dementia they are going to be forgetful, so they’re not going to remember what brought them peace two hours ago, where with chronic illness you would remember, ‘Okay my prayers helped me, I’ll say those again.’ So they don’t have that ability to say ‘Well, that would help me.’” [Participant 22]</p> <p>“So someone with cancer knows that they’re going to have many challenges down the road, but they may still have the ability to think and process and have faith or have other supports in their life. You don’t have that promise with dementia.” [Participant 14]</p>
Theme 2: The need for spiritual intervention at the mild stage of dementia	
2a. Awareness in mild dementia and its influence on spiritual distress	<p>“I’ve definitely encountered just more, I think, spiritual distress [in mild dementia] ... they’re still aware of what they had and of what they’re losing. So there’s just a level of pain that they experience around that, that I just don’t encounter very much with folks in later stages who are often on skilled nursing and are residents.” [Participant 5]</p> <p>“I would say for the person experiencing dementia it’s [the mild phase is] probably the most troubling season of dementia. There are later parts of dementia that I think are much harder on the caregivers, but when someone has the awareness that they are losing their ability to remember, they’re losing their ability to care for themselves and function independently, that involves so many deep questions of personhood, of spirit, of relation to others.” [Participant 14]</p> <p>“Most of the time they [persons living with mild dementia] ... have a self-awareness of their own dementia. And that is really difficult because they’re confused, they know they’re confused. Or if they don’t know they’re confused, there’s the sense of unease, something’s not quite right. So that’s really, really difficult.” [Participant 24]</p>

Table 2. Continued

Subtheme	Participant quotes
2b. A window of opportunity	<p>“So I think that work is—could be really important to do with mild dementia where people can still access a lot of those cognitive functions of what’s been important, what do you want to leave behind in terms of values, lessons, meaning for the people that you love.” [Participant 15]</p> <p>“I think their [persons’ living with mild dementia] sense of spirituality and spiritual care is really important at that stage because it could help them in the journey. It could help them maybe ease their fears or, even if they’re still fearful, to maybe—just to process it ... when they can still process it.” [Participant 18]</p> <p>“...if things aren’t addressed when there’s a window ... there is something really lost. There’s a finite time where things are as accessible. And I think the more we can ground people [with dementia] in their spirituality while they’re still able to process things ... we’re helping give them the longest time possible to celebrate that aspect, which is so much a part of who they are. And the longer they can hold onto that, the more we add to the quality of their lives and the dignity of their lives.” [Participant 11]</p>

dementia’s intransigence differentially causes grief, a reaction to spiritual loss. The lack of hope for recovery with dementia (vs the hope of recovery with traumatic brain injury) leads to grieving over the progressive and irreversible loss, reinforcing dementia’s classification as a terminal illness.

Subtheme 1d: impacted ability to access faith in dementia

Several participants contrasted the ability to access faith as a form of spiritual support in physical disease to a waning ability to do so in dementia. This impaired ability may manifest as declining recall of one’s usual supports or one’s reduced capacity to capitalize upon these supports. A participant related this former perception when reflecting on physical disease as a counterpoint; they described how it is not certain that a person living with dementia will have the “insight” into available spiritual resources. Another participant shared a similar viewpoint when contrasting dementia’s memory lapses with the lack of such lapses in other chronic illnesses. This participant felt that persons living with dementia lose their ability to remember what typically provides them with support, such as saying prayers; thus, access to faith is limited by not remembering what spiritual resources exist. Another participant saw a different mechanism disabling faith access in dementia. Cognitive impairment in dementia (as opposed to cancer) may, by definition, translate into limited capacity to enact faith, enactment that requires more cognitive reserve to be an accessible resource. This phenomenon may leave persons living with dementia without previously effective spiritual supports.

Theme 2: The Need for Spiritual Intervention at the Mild Stage of Dementia

This emergent theme included (2a) the spiritual distress accompanying awareness of one’s condition and (2b) the opportunity to ameliorate this distress while cognitive functioning can still be effectively utilized. Most

participants’ related comments supported this theme, with one participant stating that it was difficult to generalize across individuals with mild dementia.

Subtheme 2a: awareness in mild dementia and its influence on spiritual distress

Multiple participants felt the mild stage of dementia was unique compared to later stages. Persons living with dementia at the mild stage may have awareness of their deficits; this awareness of their ongoing losses and confusion may compound the potential for spiritual distress. A participant described this viewpoint, highlighting how such awareness leads to more spiritual distress than in later stages of dementia. Another participant had a similar perception, adding that awareness earlier in the dementia process rendered spiritual distress more salient for persons living with dementia than for caregivers. An additional participant corroborated this point, adding that, even if awareness of dementia is attenuated, persons living with mild dementia can sense their own confusion, which leads to significant spiritual distress. Contrasting with this subtheme, however, one participant did not perceive the mild stage as impacting spiritual distress per se, noting that some persons living with dementia deny the presence of their impairments.

Subtheme 2b: window of opportunity

Participants also felt that the mild phase of dementia marked a unique opportunity for spiritual intervention within the illness trajectory. A participant noted the value of spiritual care at this phase. By intervening early, persons living with mild dementia can be assisted with spiritual concerns such as leaving behind a meaningful legacy as the end of life approaches. Additional participants highlighted the importance of such intervention at the mild phase even further. A participant emphasized the potential for spiritual care to support persons living with mild dementia who are experiencing the frightening process of decline while they are aware. Another participant underscored how

time-dependent the “window” for spiritual intervention for dementia is. Not capitalizing on cognitive processing while it remains represents a missed opportunity for prolonging the “quality” and “dignity” of individuals’ lives.

Indeed, those with mild dementia may still have the capability to engage in spiritual intervention with only minimal supports, which may become more challenging with more dementia severity. It is necessary to seize this time-sensitive opportunity when awareness may exist and when capacity exists to process such distress. In such a manner, stakeholders would be able to optimize quality of life for those with dementia.

Discussion

This study qualitatively explores salient spiritual needs in dementia from the perspective of health care providers. The emergent themes and subthemes shed light on several types of intervention implications: the “what,” “who,” and “when” of dementia-focused spiritual care (see Table 3 for the thematic structure with types of intervention implications). First, theme 1 depicts how spiritual experience in dementia differs from that of a variety of other medical conditions. These findings have important implications concerning the “what” (related to the subthemes: fear in dementia, profound loss of self in dementia, progressive and incurable nature of dementia) and the “who” of dementia-focused spiritual care (related to the subtheme: impacted ability to access faith in dementia). Theme 2 surfaced as the need for spiritual intervention specifically at the mild stage of dementia with the following subthemes: awareness in mild dementia and its influence on spiritual distress, and a window of opportunity. In this case, the findings point to implications for the “when” of care provision. We will next review the implications of each of these findings.

To begin, our work found similar findings to other research about the “what” of spiritual care while also

building upon those findings. Consistent with this study, other literature has noted that fear plays a strong role in the dementia experience (Daly & Fahey-McCarthy, 2014). Other literature has also described the role of fear in other medical conditions, which can engender spiritual distress, particularly in terminal conditions like cancer (Puchalski et al., 2019). Our participants’ perspectives advanced these previous findings by comparing the two sets of experience (i.e., in dementia vs in other serious illnesses). Our participants argued that, comparatively, fear is one of the most highly salient features of dementia, causing notable spiritual distress. Our findings also reinforce the spiritual salience of dementia-related loss of self as found in other research (Dalby et al., 2012). While loss more generally may play a role in terminal illness (Chen et al., 2018), we found in contrast that loss of self is a highly salient spiritual crisis in dementia. As one of our participants emphasized, this disruption in self-identity is the primary spiritual challenge in dementia, leading to a disruption in relationship with one’s self, other persons, and God.

The field should consider designing spiritual care with these spiritual needs (fear and concerns of loss of self) in mind. Spiritual interventions for dementia exist to date, but no one intervention targets both of these primary needs. First, Dignity Therapy directly acknowledges the need for maintaining a sense of identity but not for mitigating fear. Specifically, the intervention was developed to alleviate psychosocial and spiritual distress in persons near the end of life (Chochinov et al., 2005; Hall et al., 2012) and has also been applied in the dementia context (Chochinov et al., 2012). It is a psychotherapeutic approach that uses documentation of life events and personal information for purposes of leaving a legacy. A randomized controlled trial has assessed Dignity Therapy with older adults in nursing homes, yet it did not examine specifically the intervention’s impact on persons living with dementia (Hall et al., 2012). Spiritual reminiscence therapy is another spiritual intervention used in dementia and rooted in the belief that each person living with dementia has their own identity and sense of self (MacKinlay & Trevitt, 2010). Such therapy aims to maximize spiritual well-being and minimize anger, guilt, and regret by helping recipients reconnect with and build upon their life’s meaning. Within a randomized controlled trial, 6 weeks of the intervention resulted in successful outcomes (i.e., improved hope, life satisfaction, and spiritual well-being) for persons living with mild or moderate dementia (Wu & Koo, 2016). Again, addressing a sense of fear is notably lacking from this intervention’s scope. There is also the Namaste Care program, which actively attempts to instill calm in its recipients (arguably an approximation to easing fear) but not to preserve a sense of identity. The program was initially developed for care of persons with advanced dementia living in nursing home settings (Simard, 2013). This program seeks to “honor the spirit

Table 3. Thematic Structure With Types of Intervention Implications

Theme and subtheme	Type of intervention implications
Theme 1: Spiritual experience in dementia differs from that in other medical conditions	
1a. Fear in dementia	“What”
1b. Profound loss of self in dementia	“What”
1c. Progressive and incurable nature of dementia	“What”
1d. Impacted ability to access faith in dementia	“Who”
Theme 2: The need for spiritual intervention at the mild stage of dementia	
2a. Awareness in mild dementia and its influence on spiritual distress	“When”
2b. A window of opportunity	“When”

within” of persons living with dementia by meeting their physical and spiritual needs with soothing, multisensory experiences and meaningful activity. A recent feasibility cluster randomized controlled trial found, from staff and family report, that the program was acceptable and led to heightened levels of social engagement and levels of calm among nursing home residents living with advanced dementia (Froggatt et al., 2020). Given the gap in targeting both fear and loss of self in these dementia-focused efforts, future spiritual interventions and care by providers, community clergy, family, and friends will need to directly address these spiritual concerns to bolster spiritual well-being. Also worthy of note are interventions outside the field of spirituality. The Preserving Identity and Planning Advance Care intervention focuses on identity, fear, and connection in mild dementia but has not yet been conceptualized as spiritual care (Hilgeman et al., 2014). Interventionists could broaden the scope of such an intervention in the future.

Other research, similar to this study, has commented on the progressive and incurable nature of dementia and argued that the field has not sufficiently recognized dementia as a terminal illness (van der Steen et al., 2014). Our participants contrasted dementia with nonterminal illness, underscoring how the terminal nature of dementia potentially leads to spiritual distress around acceptance of one's condition, loss of control, and grief. These findings reinforce the call for palliative care to include persons living with dementia as service recipients (van der Steen et al., 2014). In this case, the implication for dementia-appropriate care is the need to leverage this already existing care model rather than “reinventing the wheel.”

From our subtheme of impacted access to faith in dementia, we also gained insight into the “who” of spiritual care; that is, in dementia, there may be heightened need for assistance from others to access faith. With other serious illnesses, like cancer, it can be hard to access spiritual resources like faith communities due to feeling ill and being less mobile (Balboni & Balboni, 2018). In dementia, however, these barriers may be compounded further. While the spiritual nature of persons living with dementia is not lost (Daly & Fahey-McCarthy, 2014; Everett, 1998), our participants underscored how progressive loss of cognitive abilities impede independent access to spiritual aid. Such access might be facilitated by others, by assisting with and reminding persons living with dementia of religious service attendance, prayer, and other rituals; and by making religious and spiritual rituals dementia-friendly. While our findings do not directly address the “how” of dementia-friendly spiritual care, conceptual papers in the field have embellished these ideas further (Biggar et al., 2019; McFadden, 2021). That is, dementia-friendly spiritual care is characterized in part by being familiar in content, being spoken slowly and with simplicity, and using multisensory experiences such as spiritually evocative

images and music from the person's past (Daly & Fahey-McCarthy, 2014; Ryan et al., 2005)

Following from the salient spiritual experience in dementia established in our first theme, findings related to our second theme weighed in on the optimal timing of spiritual intervention in dementia. In this latter theme, findings pointed to individuals' potential awareness or sensing of their declining cognition in early dementia and how such perceptions could heighten spiritual distress at that phase in particular. In a couple of contrasting examples, our participants mentioned that awareness of one's own illness was not present or that denial was predominant. Indeed, it is well established that lack of awareness or denial may be present among those with dementia (Alexander et al., 2019). Regardless, our findings uniquely point to the need to grant persons living with dementia the benefit of the doubt; we need to be prepared to address spiritual distress and promote spiritual well-being when either explicit or implicit awareness of one's own cognitive challenges may be present.

Indeed, this study found a compelling opportunity to intervene with spiritual care early in the dementia experience. This finding relates in part to the awareness that might be present and be causing spiritual distress as mentioned just above. Additionally, our participants emphasized the imperative of intervening early given the time-sensitive nature of cognitive decline. The narrow “window of opportunity” we found is also alluded to in other dementia research. For example, research has focused on the need to conduct advance care planning and palliative care, more generally, earlier in dementia (Song et al., 2019; van der Steen et al., 2014). Books, literature reviews, and exploratory work have also explored the need for spiritual care in early phases of dementia (Beuscher & Beck, 2008; Chen et al., 2019; Jewell, 2011; Thibault & Morgan, 2017); yet, empirical research on the topic is sparse, and thus research development is still early in the pipeline (Palmer et al., 2020). The field still needs to strive for a person-centered approach to support spiritual well-being by (a) recognizing spiritual distress in dementia when it is particularly poignant and (b) doing so when the individual may still be able to participate in facilitated processing of his/her own distress.

Limitations

This study has a number of limitations that future research should address. An important limitation relates to the use of health care providers as proxies for persons living with dementia; we do not know the extent to which the participants' observations authentically reflect the spiritual experience of persons living with dementia or not. That is, persons with dementia may perceive their own spiritual needs differently from their providers; for example, an author living with dementia has described a sense of self that is intact; accompanying fear derives from *others'* perceptions that she has lost her identity

(Bryden, 2020). To address this important limitation, direct report from persons with dementia and their families regarding spiritual needs in dementia is critical for the field. The perspectives of providers to persons living with dementia is nevertheless important: these providers have broad and intensive hands-on experience of differing medical conditions and stages of dementia, offering an essential understanding to inform our research question and future intervention work.

Future interview guides on this topic should also probe for specifics that our interview guide did not: (a) person-level spiritual experiences in dementia (rather than just higher-level reflections on spiritual experience) and (b) discussion of how perspectives on spiritual experience in dementia may be similar or differ by varying faiths. Further, our interview guide did not provide an explicit definition of “spiritual needs” at the outset of the interview. This omission might help to explain why a few participants did not report having observed spiritual needs in persons living with dementia; this finding suggests that future qualitative studies on this topic should define spiritual needs upfront. Providing a definition across all participants might lead to more consistent findings.

Furthermore, our qualitative findings may not be transferable to other contexts, settings, or persons. In particular, our sample was homogeneous in race, ethnicity, and education level; though there was variety in religious affiliation of chaplains, these affiliations did not extend beyond Jewish and Christian traditions. This homogeneity limits the perspectives gathered in terms of demographics. For example, the religious affiliations of participating chaplains may mean that findings did not apply to persons living with dementia of other faiths; this limitation may be somewhat counteracted, however, by several of the chaplains having been trained to work in an interfaith setting. Meanwhile, the heterogeneous types of settings from which participants were recruited may have led to different findings than recruiting participants from a narrower group of settings would have had. Future studies should conduct qualitative inquiry with these two sampling limitations in mind. Additionally, we are unable to confirm for one of our participants whether they had experience serving both persons living with dementia and persons living with other medical illnesses. Such experience is important to providing an informed perspective on this work’s first analytic theme; we did not find this participant’s responses to affirm or contradict theme 1’s findings, however. Given the timeline and scope of this pilot study, we were also limited in our ability to complete more interviews; even so, thematic saturation was achieved as redundancies emerged in the themes across the 24 interviews performed.

Conclusion

This qualitative study gathered health care providers’ views on salient spiritual needs in dementia. We found that the salient elements of spiritual experience in dementia are hard

for individuals to mitigate independently and that spiritual distress may be particularly salient with self-awareness, making early stages of dementia a vital time to intervene. In sum, our findings shed light on potential avenues for the “what,” “who,” and “when” of spiritual care in dementia. Future research could design and test a number of initiatives in line with our findings. All of these initiatives should begin early in the dementia process. Training chaplains and spiritual care providers in long-term care settings, community clergy, faith community members, and family and friends in the what, who, and when of dementia-appropriate spiritual care could play a vital role as well. Such training will need to be stakeholder-specific, accounting for varying levels of expertise or lack thereof in issues of dementia and of spiritual care. Collaboration among all these stakeholders could also be critical, with referrals necessary to health care chaplains in cases of less straightforward spiritual distress. Additional work could build upon our comparison of *differing* spiritual needs across dementia and other medical conditions to *similar* spiritual needs across them. This effort would verify not just what dementia-specific customizations need to be incorporated in spiritual care for dementia, but also what common “ingredients” might be needed.

Finally, future empirical studies need to advance our understanding beyond the what, who, and when to the “how” of spiritual care for dementia. Narrative-oriented spiritual interventions that often are successfully used with other illnesses (Chen et al., 2018) may not be feasible or most effective with the cognitive and linguistic deficits in dementia. A dementia-appropriate form of spiritual care, as well as content and timing, will be essential to meet the salient spiritual needs in this population; researchers will need to examine how to tailor the form, content, and timing to spiritual needs across the spectrum of mild, moderate, and severe dementia. With all this information in hand, we could better prepare health care teams to meet the spiritual needs and thus promote the quality of life of the tens of millions of individuals living with dementia across the globe.

Supplementary Material

Supplementary data are available at *The Gerontologist* online.

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Conflict of Interest

None declared.

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