


Article

Does God Work in All Things to the Good of Those Who Love Him? Family Caregivers of Persons with Early-Stage Dementia Share Their Spiritual Struggles

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Abstract: Spiritual struggles are distressing thoughts, feelings, or shifts in behaviors pertaining to faith/life philosophy in response to traumatic/stressful experiences. There is limited research on this phenomenon among family caregivers of persons in the early-stages of dementia (PWD). The purpose of this qualitative study, therefore, was to better understand spiritual struggles in this population. Using Interpretative Phenomenological Analysis, we analyzed interviews of 28 caregivers of PWD in the early stages. There were three broad areas for spiritual struggles in their narratives: (1) transpersonal spiritual struggles (e.g., struggles with God or a higher power in the context of caregiving); (2) interpersonal spiritual struggles (e.g., struggles with communities of faith related to the lived experience of being a caregiver of a loved one with dementia); and (3) intrapersonal spiritual struggles (e.g., struggles around beliefs, morality or ultimate meaning related to caregiving). Themes and subthemes under each of these areas are expounded upon. The importance of identifying/addressing spiritual struggles among family caregivers of PWD and areas for future research are highlighted.

Keywords: dementia; caregiving; spiritual; religious; faith; coping; struggles



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1. Introduction

Two years ago, Carolyn's mother, Francis, had a severe urinary tract infection and ended up in the hospital for treatment. Around the same time, she started to have changes in her memory and concentration, and the hospital physician said she might have had a "mini stroke". Over the next year, Francis's memory changes became more apparent, and she started to miss appointments and important events like birthdays, ask the same questions over and over, and would only eat sweets or nothing at all. She started to feel sad and stopped working on a book she was writing. She withdrew from some of the important people in her life like her best friend Tonya. Kenneth, Francis's husband, became alarmed and took her to a neurologist who diagnosed her with Alzheimer's disease. In explaining the possible progression of the disease, the neurologist said Francis could, over time, eventually not know who she or anyone else is and "fade away"—that there was no cure for this disease. Kenneth, a highly religious man, was involved with a bad business deal right before Francis started to have symptoms. He told Carolyn that he wondered if God was punishing him for these business deals by "giving his wife dementia." He cried and said that he was losing the brightest most wonderful woman in the world and pleaded for God's intercession. "Why God, would you do this to Francis?", he prayed. "Please give me the dementia instead of her . . . Don't you still love my family?" Francis broke down and said, "Will I still be a person if I no longer know who I am?" Carolyn suggested making an appointment with their pastor for support. However, Kenneth said that he was concerned that people at the church might treat he and Francis differently if they found out

that Francis was diagnosed with a dementia. Kenneth and Francis stopped going to church and became isolated. Carolyn felt powerless. She wondered whether life meant anything after all.

We begin this article with the above illustrative account of a family's spiritual response to a dementia diagnosis in the beginning stages. This account is a compilation of narratives from clinical practice rather than representing a specific family. As you can see, this family is grappling with profoundly spiritual questions. The nature of one's personhood or that of a beloved may come into question as well as concerns about meaning and ultimacy. Aspects of daily life, such as attending church or important strivings and activities, may also be affected—as well as relationships with family, friends and one's spiritual community. For religious persons, the relationship with God or a higher power may come into question within this context—potentially shaking the person diagnosed with dementia and their family members to the core.

In this article, we examine “spiritual struggles” among family caregivers of persons in the beginning stages of a dementia through their narratives. Spiritual struggles have been defined as experiences of tension, conflict or strain that center on whatever people view as most sacred in their lives (Exline 2013; Pargament et al. 2005b; Pargament and Exline 2020; Pargament and Exline 2022). There is a growing body of evidence that spirituality can serve as a coping resource for persons diagnosed with a dementia and their family members (Giannouli and Giannoulis 2020). However, there is limited systematic research on the nature of spiritual struggles among family caregivers particularly those who have loved ones in the early stages of disease progression (McGee et al. 2021b).

The purpose of the current qualitative study, therefore, was to gain a deeper understanding of this phenomena among family caregivers of PWD using Interpretative Phenomenological Analysis (IPA) of semi-structured interviews. Before we delve into relevant background information for this article, it is important to note that we are not referring to spiritual struggles in a theological sense or trying to determine ultimate truth from a religious viewpoint. We are instead approaching the construct of spiritual struggles through a psychological lens and thus examining the perceptions of caregivers of PWD.

2. Impacts on Family Caregivers of Persons Living with Dementia

Progressive dementias, such as Alzheimer's disease, have been poignantly referred to as “theological” diseases (Keck 1996) in that PWD and their family caregivers may grapple with profound questions of meaning and purpose in the wake of a dementia diagnosis (Robinson et al. 2011). Family caregivers face unique challenges balancing their loved one's care needs, family life and other relationships, work responsibilities, and self-care (Schulz and Eden 2016).

Observing progressive changes in a loved one's physical, cognitive, emotional and functional status may lead to strong emotions in a family caregiver (Bons-Storm 2016). Compared to family caregivers of older adults who do not have chronic health conditions, caregivers of PWD tend to report lower subjective quality of life and higher levels of distress (Schölzel-Dorenbos 2011; Schulz and Eden 2016). As compared to professional caregivers, such as nurses and home health workers, family caregivers of PWD often lack the training or support required to navigate or anticipate the changing needs of their loved ones (Aston et al. 2017).

Caregiving impacts all spheres of life such as employment, finances, free time, social relationships and spirituality among others (Evans and Lee 2014; McGee et al. 2021a; Shuter et al. 2014). Up to one third of family caregivers report anxiety and/or depression, suggesting a significant mental health toll related to the caregiving experience (Schulz and Martire 2004; Sheehan et al. 2021). In addition, caregivers are at risk for developing stress-related health problems such as hypertension, heart disease, and compromised immunity (Rahman et al. 2019; Vitaliano et al. 2005). A sense of perceived burden may emerge due to the ongoing stressors associated with caregiving (Armstrong et al. 2019; Schulz and Eden 2016; Thompson et al. 2005).

Likewise, the caregiving experience can be punctuated by episodes of profound grief and loss as a PWD changes cognitively even though they appear to be physically well (Kevern 2010). Unpredictability of mood and behavior in PWD may be frustrating or irritating to family caregivers resulting in feelings of shame or guilt (Cooper and Livingston 2014; Schulz and Eden 2016). Other changes such as wandering, emotionality, and changes in how a PWD interacts with other people may add to caregiver distress (Pinquart and Sørensen 2007). Some caregivers worry about their ability to care for their loved one with dementia if they were to become sick or even die (Bons-Storm 2016).

3. Spiritual Struggles

Traumatic or stressful life experiences that threaten what a person considers sacred, or most important in their lives, may lead to a spiritual struggle (Pargament et al. 2005b; Pargament and Exline 2020). In non-caregiver populations, spiritual struggles are embedded with existential concerns and are diverse in their expression (Exline 2013; Pargament et al. 2005b; Pargament and Exline 2020). In the research literature, three predominant areas of spiritual struggles have been written about in non-caregiver populations (although these areas may not be mutually exclusive or exhaustive): (1) Struggles with the Divine (e.g., may focus on God, gods, other supernatural beings or higher powers); (2) Interpersonal Spiritual Struggles (e.g., relationships with other people, groups, organizations, or institutions); and (3) Intrapersonal Spiritual Struggles (e.g., internal values, beliefs, feelings, and practices). A person can experience one or more of these larger themes of spiritual struggle in response to a life circumstance.

3.1. Struggles with the Divine

In the wake of a traumatic or life altering experience, a person's previously held positive perceptions of their relationship with the Divine may change. These struggles can manifest as religious discontentment, an ominous worldview, or conceptualizing God or a higher power as punitive (Pargament 2007). The effects of an insecure relationship with God or a higher power are varied and can include doubting God, feeling lost spiritually, and feeling dissatisfied or angry with God (Pargament 2007). An insecure relationship with the Divine may impact a person's ability to engage fully in religious and spiritual coping strategies (Desai and Pargament 2015).

Drawing from Froese and Bader's (2010) work on the different conceptualizations of God's character, it is possible that caregivers might question or adapt their view of God's character in response to living with dementia. Indeed, there are several instances in the caregiver literature in which Christian caregivers grapple with the previously held belief of God's benevolent involvement in their lives and start to question if He is instead critical and punishing (Bons-Storm 2016; Kevern 2010).

3.2. Interpersonal Struggles

A crisis of meaning can potentially impact all dimensions of a person's life including interactions with others. Changes in an individual's involvement with their faith community may occur leading to variation in involvement with previously valued religious and spiritual practices (e.g., worship, prayer, reading religious or spiritual texts, etc.). When experiencing a crisis in meaning, some persons tend to increase their personal religious or spiritual practices or involvement with their faith community to gain comfort and reestablish a sense of meaning (Desai and Pargament 2015; Warner et al. 2009). Other religious or spiritual people, however, may respond to the crisis of meaning by avoiding participating in religious and spiritual practices or involvement with their faith community (Desai and Pargament 2015).

Among family caregivers of PWD, there are documented struggles in this domain centering on painful interactions with faith communities. For example, some faith communities do not know how to accommodate a PWD's behaviors, such as noise disruptions during religious services or changes in sociability (McGee and Myers 2014). These encounters can

lead caregivers and their loved ones to experience feelings of shame and judgement from fellow congregants as well as avoidance of engaging with faith communities (Garrison 2021; McGee et al. 2021b). There also may not be specialized resources in faith communities to accommodate the needs of family caregivers or their loved ones with dementia (Plunkett and Chen 2016).

3.3. Intrapersonal Struggles: Core Beliefs, Assumptive Worlds and Sacred Loss

A person's "assumptive world" is comprised of core beliefs about the self and the world that orients personal reality (Kauffman 2002). Changes to one's assumptive world may result in a "crisis of meaning" and subsequent spiritual struggle. For example, the beliefs that "the world is just" and "good things happen to good people" can be shattered in the wake of a traumatic experience (Janoff-Bulman 2011). For some, assumptive worlds also include ideas about the Divine's character, leading to concepts of God as potentially authoritative, distant, or critical rather than benevolent (Froese and Bader 2010).

Religious or spiritual persons can experience spiritual struggles when they must resolve conflicts between their core beliefs about God's benevolent control over their lives and the reality of their current life circumstances (Desai and Pargament 2015; Mahoney et al. 2003). In non-caregiver samples, persons may either override their difficult experiences with new revelations and reestablish their original beliefs, or adjust their worldview to exclude or replace previously held religious or spiritual beliefs (Kevern and Stifoss-Hanssen 2020).

A sense of loss or desecration of something considered sacred can lead to decreased engagement in religious and spiritual coping and psychological distress in general populations (Matthews and Marwit 2006). Desecration perceptions can result in anger and viewing a stressor as uncontrollable or unjust (Mahoney et al. 2003; Pargament et al. 2005a). The perception of sacred loss may be accompanied by symptoms of depression, anxiety, and painful feelings such as self-blame and negative thinking patterns (Pargament et al. 2005a; Warner et al. 2009).

Among caregivers of PWD, negative appraisals of their caregiving experience are connected with similar symptoms, including depression and anxiety (Crellin et al. 2014). In a recent quantitative study, spiritual struggles among family CGs of PWD were associated with more depressive symptoms and a greater sense of caregiver burden (Wong and Pargament 2019). A mixed methods study found that family caregiver ratings of the frequency and severity of neuropsychiatric symptoms in their loved one (e.g., delusions, hallucinations, agitation, disinhibition, and nighttime disturbances) were tied to personal spiritual struggles on a self-report measure (McGee et al. 2013).

4. Research Design and Methods

Institutional Review Board (IRB) approval was obtained prior to all research activities.

4.1. Criteria for Participation

Inclusion criteria for the study were: (a) family caregiver of a person diagnosed with a dementia (in the early stages per comprehensive neurological and neuropsychological evaluation); (b) PWD within 2 years of a dementia diagnosis; (c) over the age of 21 (given that we were interested in learning about adult caregivers (not child or adolescent caregivers)); (d) fluent in English; and (e) willingness to engage in a semi-structured interview. Exclusion criteria were: (a) personal diagnosis of a dementia; (b) untreated serious mental illness (e.g., schizophrenia or bipolar disorder); and (c) difficulty understanding or engaging in conversation due to challenges with comprehension or expression.

4.2. Participants

Twenty-eight family caregivers of persons with early-stage dementia the most frequent diagnosis being Alzheimer's disease participated in the study. Approximately 60% of the sample were women and 40% were men. The average age of study participants was 78.26

(SD = 9.88). Self-reported racial identity was primarily Caucasian (92.9%). Educational status was high with most participants having earned at least a bachelor's degree. Most participants self-identified as Protestant or Roman Catholic Christians in this sample. There were not any participants who identified as Eastern Orthodox. Among those who identified as Protestant, several denominations were represented (e.g., Methodist, Episcopal, Presbyterian, Baptist etc.). There was one participant who identified as a Spiritualist and one as agnostic.

4.3. Recruitment

Participants were recruited from an Alzheimer's Disease and Memory Disorder Center at a medical school and other community agencies who serve PWD and their family caregivers in a large metropolitan area in the Southwestern region of the United States. IRB approved flyers describing the study were distributed by staff members of these organizations to potential participants. These flyers shared that the researchers were interested in learning about how spirituality and positive psychological factors influenced the lives of persons with dementia and their family members. Persons who were interested in participating in the study were screened for eligibility on the telephone. An in-person appointment was scheduled for the purposes of informed consent within 1–2 weeks of screening if a person expressed interest in participating in the study.

4.4. Instrument

After the consenting process, participants received the Dimensions of Caregiving Interview (DCI; McGee et al. 2013). The DCI is a semi-structured interview protocol that asks specific questions aimed at understanding a range of thoughts, feelings, and experiences among caregivers of persons with dementia. The DCI was initially developed as an instrument for qualitative research inquiry. DCI instructions require interviewers to ask standardized questions of interviewees in a certain order with the opportunity for seeking clarification. Prior to developing the DCI, the research team was unable to identify a published interview protocol for use with caregivers that sought to better understand their lived experiences from a spiritual and positive psychological perspective.

The DCI was developed with input from an interdisciplinary team of subject matter experts with clinical and/or research expertise in the areas of dementia and caregiving. Clinical subject matter experts included a neuropsychologist, nurse practitioner, physician, and social worker. Research subject matter expertise was provided by a gerontology researcher and a psychology of religion researcher. After initial development, the DCI was piloted with an advisory panel of three caregivers for acceptability. Their feedback and suggestions on content and the degree to which the questions were worded clearly and sensitively were integrated into the final version of the DCI. The DCI has not yet been examined for its psychometric properties (e.g., internal consistency reliability, inter-rater reliability, construct validity, etc.).

4.5. Procedure

Two interviewers received DCI training (which included practicing the interview). Interviews were conducted in a private office space, audio recorded, and lasted 45 min on average. Interviewers and participants had not met prior to the interview to reduce bias.

4.6. Design and Data Analysis

To gain a deeper understanding of spiritual struggles among family caregivers of PWD, interpretative phenomenological analysis (IPA) of semi-structured interviews were utilized. The advantage of an IPA approach was the opportunity to examine the inner-most deliberations of participants and make an interpretation of the meaning of their lived experiences (Alase 2017; Smith et al. 2022). IPA is a particularly useful methodology for examining emotions and complex religious/spiritual issues among populations dealing with health related concerns (Pietkiewicz and Smith 2014).

Interviews were professionally transcribed, audit checked, and uploaded to NVivo (QSR International Pty Ltd. 2022). The IPA procedures set forth by Smith and colleagues (2009) were utilized for analyzing the interviews. Four members of the research team gained insight into the data by reading the caregiver narratives multiple times, making notes and then developing initial codes that represented common words or sentences in the transcripts. Three members of this team then independently conducted line-by-line coding. These codes and their definitions served as the basis for forming themes. The team discussed the merits of each code and whether to retain, refine, merge, or eliminate codes as warranted. Codes were organized on a hierarchical continuum (general/abstract to specific/descriptive).

The team conducted four additional team meetings to process insights from individual analysis and triangulate the data (Alase 2017; Nowell et al. 2017). The team grouped codes into 'meaning units' that captured the core essence of participants' lived experiences. Next, the team interpreted the data to develop themes that gave meaning to what it was like to have a spiritual struggle as a family caregiver of a PWD. This iterative process of text-to-code and code-to-code revision was conducted for the purposes of increasing the trustworthiness of the findings (Creswell 2013; Merriam 2002). Additionally, the data from the interviews, observations, and field notes were triangulated to provide contextual accuracy.

5. Findings

5.1. Overview

The caregivers in this sample were willing to share their spiritual experience(s) in the context of caregiving. To be considered a spiritual struggle, participants had to verbalize having had a distressing spiritual experience, thought, feeling or behavior in relation to caregiving. When asked directly, "have you had any spiritual struggles since becoming a caregiver?", most participants denied having experienced any struggles. In response to more indirect questions, however, almost three-fourths of participants reported experiencing a spiritual struggle.

Three broad areas for spiritual struggles and corresponding subthemes emerged related to participants' lived experiences: (1) Transpersonal Spiritual Struggles (e.g., struggles with God or a higher power in the context of caregiving); (2) Interpersonal Spiritual Struggles (e.g., struggles with communities of faith related to the lived experience of being a caregiver of a loved one with dementia); and (3) Intrapersonal spiritual struggles (e.g., struggles around morality or ultimate meaning from the perspective of caregiving). One or more of these areas for spiritual struggle were mentioned by most of the caregivers in this sample. For some caregivers, the struggle(s) were partially or completely resolved by the time of interview. For other caregivers, the spiritual struggle(s) they shared were ongoing.

5.2. Transpersonal Spiritual Struggles or Questioning God or a Higher Power in the Context of Caregiving

Previously held assumptions about the nature of God were brought into question in the context of the caregiving experience. Questioning why dementia could happen if God is loving and benevolent, feeling a sense of injustice or being let down by God, feeling angry towards God, feeling abandoned by God, and wondering if God was punishing the family were present in this sample. Additionally, several caregivers felt impeded in their relationship with God due to the shame and guilt they experienced from even having these questions about God. Indeed, several caregivers shared that they were intentionally avoiding engaging with the Divine. For example, one caregiver described her current relationship with God as "a standoff".

Questioning why God would allow dementia to come upon a good family emerged as a subtheme. For example, a daughter whose mother was living with Alzheimer's disease said: "I've never seen my mom do anything that wasn't good and nice and I wonder why—I do. I wonder why this would happen to her [of all people] and I do ask God why".

The mother had been considered among the most loving of persons and her daughter could not fathom how God could inflict such suffering upon her. A son of a father diagnosed with dementia explained: “spiritually you wonder why this has happened, especially with my dad. My dad was a Deacon in the church for thirty years, the Catholic church, and basically really devoted his life to that . . . he really spent most of his time helping others there . . . even more than spending time with the family. So you wonder, you know, why would God want to take a guy who did so much for so many people?” This son could not understand why God would allow his father to have dementia when he had sacrificed so much of his life to the Church—even at the expense of his own family.

Another subtheme, in this sample, was a sense of injustice or being let down by God, which was manifest through the emotion of anger in the context of a life interrupted: “so did I get mad ‘Hell, yes.’ This is not what I planned, we got money in the bank and we’re gonna do this, this, and this and now you’re telling me we’re not.” This spousal caregiver and his wife had spent much of their years preparing for retirement and felt as though God had taken their family’s plans away. Another spousal caregiver shared: “I mean who wouldn’t say, “Daggummit”. I’ve been up here helping with all these things and doing all this in now you [God] dump this in my lap.” An adult child caregiver shared, “Sometimes you do want to stomp your feet and jump up and down . . . and screech this isn’t fair!” when reflecting on her experience. She goes on to say: “But uh I have to admit, because of [person with dementia] condition, I have gotten angry with God . . . there is just so much pain.”

The subtheme of feeling abandoned by God was present in this sample. A spousal caregiver shared: “I don’t believe that I should be praying to God to make [my loved one] better because it is not realistic, and besides God’s got better things to do.” The belief underlying this statement was that God no longer considered the caregiver and his family important enough to provide healing combined with an understanding that Alzheimer’s disease is in fact a medical condition with no cure. An adult child of a PWD expressed her concerns that God had left her to deal with overwhelming challenges on her own: “sometimes wondering why this is happening uh with other things happening, many things happening at one time that are overwhelming, are challenges, or just um things that need to be done.” She expanded that she felt that God did not want to help her overcome her life circumstances which had involved a job loss to provide care for her family member.

Questioning beliefs about the benevolence of God led to an insecure relationship with the Divine for some caregivers as well as a reevaluation of God’s character as potentially punitive. For example, one caregiver explained: “Did I do something? Even though I didn’t think God worked that way . . . I now think He might punish us.” Another caregiver said: “It’s like, what did I do, Lord, what did I do? Why did you take my job away from me? Why did you put my mom in this condition?”. While these caregivers outwardly expressed a belief in a benevolent God, they experienced doubt about the goodness of God in light of the challenges of caregiving.

The subtheme of questioning God’s love was also present in this sample of family caregivers. One caregiver shared that “[caregiving is] one of those things where it’s real easy to say ‘how come this be happening to us?’” When asked what she meant, she went on to say that she thought God loved her family and could not reconcile this love with their experience of living with dementia.

Nearly all of the CGs experiencing struggles in their relationship with God also reported finding some comfort in God’s presence in their lives, as explained by one caregiver: “There’s a reason why he’s doing this, and I sure can’t tell him what to do.” Another caregiver found hope in this belief: “I know that He works in all things to the glory and to the good of those that love him.” This mix of responses suggest that some caregivers may have ambivalent feelings about their relationship with God, based on their caregiving experience, which could potentially lead to a sense of cognitive dissonance.

5.3. Interpersonal Spiritual Struggles and Renegotiating Engagement with Faith Communities

The caregivers in this sample found themselves renegotiating previous levels of engagement with their faith communities and spiritual practices in light of their lived experiences. In general, participation and involvement with faith communities and spiritual practices declined from pre-caregiving levels. These changes stemmed, at least in part, to the evolving level of care their loved one needed. For example, a lack of time to attend church due to caregiving responsibilities was a frequently cited obstacle. One caregiver expressed their dilemma by saying: "There's no way to be at church all the time, be with your parents all the time, be at work all the time, be a mom all the time, be a wife all the time." Several caregivers reported problems associated with traveling to church. Others reported that their own declines in physical and/or emotional energy were barriers to attending religious services or participating in previously valued spiritual practices.

Some participants in this study shared that their faith communities had inadvertently harmed or hindered them in some way after their loved one was diagnosed with dementia. Some shared that they felt outright hurt, mistreated or offended by people in their faith communities. There were examples of caregivers feeling rebuffed for sharing the experience of a struggle in one's relationship with the Divine.

The subtheme of judgement by the faith community was present in this sample. One caregiver stopped attending a Bible study group after being told that she did not have enough faith when she shared that she was not sure why God brought this experience upon her and her husband: "They, my church group, they think they have so much more faith than I do which is hurtful." Another caregiver said: "if we're out eating with the group or having lunch at the meeting or whatever I like [PWD] to get up and go fix her own plate and the people there get on me about [it], you know, you shouldn't have your Momma fixing your own plate, you should be fixing her plate, or one of them will fix her plate. I tell them, no." This caregiver wanted to give her mother as much independence as possible, even if her mother's skills at "fixing her own plate" were different and felt "guilted" by church members for doing so.

Another subtheme was not understanding or tolerating the caregiver's loved one with dementia, which was manifest through unsupportive behavior. For example, one caregiver shared that she had stopped attending church completely. When asked why she stated: "You can't go to . . . Church with [my husband]." When asked what this meant, she shared that when her husband had spoken out during a worship service, she was told that his behavior was disruptive and distracting to other congregants and that she needed to be in better control of his behavior. She went on to say, "That's really why we quit going because I get embarrassed when he does this." Another caregiver shared a painful story about deciding not to take her mother to church anymore. "I stopped going there [church] . . . I stopped taking her. To me it's awkward because of Momma's personal habits now—passing gas or just belching, you know. I know she can't help it because the doctor told me that. What I chose to do, because the church is a small church, the building itself, because of that I stopped taking her there." Lack of patience for PWD also emerged as one caregiver said: "But the patience comes in with other people who are not patient with mom. A lot of bite my tongue, because they don't understand."

Several caregivers shared that their faith communities either avoided the topic of dementia or spending time with the caregiver and their loved one. One caregiver said: "please just talk to us" when sharing how she thought her fellow congregants were ignoring her and her husband who had Alzheimer's disease. She went on to share that this was embarrassing and hurtful to her loved one who felt stigmatized once the faith community became aware of his dementia diagnosis. However, it is important to point out that all but one caregiver in this sample also provided examples of ways that their faith communities had been supportive such as providing physical assistance or listening compassionately to their concerns.

Some caregivers reported that their faith communities were neither a support nor a hindrance, either because the caregiver had not informed the congregation that their

loved one was diagnosed with dementia or because the caregiver was not involved with a faith community. Multiple caregivers shared that their loved one “doesn’t want anyone to know” and had therefore not informed their faith community of the diagnosis and related concerns. Regardless of the reason, these caregivers lacked the support of a community of faith during their early caregiving journeys—as did their loved one with early-stage dementia.

5.4. Intrapersonal Spiritual Struggles: Dissonance between Core Beliefs and the CG Experience

Dissonance between core religious beliefs and the experience of caregiving was a common theme in this sample. Most caregivers who had a spiritual struggle in this area indicated that these struggles were transient rather than long-lasting.

One subtheme that emerged in this sample had to do with the meaning of self-sacrifice from a religious perspective in the context of caregiving. One caregiver described his role “as my cross to bear” while another referred to caregiving as a “test” from God to “sacrifice” his own needs for the needs of his loved one. Some caregivers admitted that they were not capable of fulfilling this “calling from God” or that they did not want the responsibility. As reflected by this caregiver’s comment: “[my greatest challenge] might be it—my own psychological guilt of wishing I didn’t have this duty.” In addition, some caregivers experienced guilt over engaging in self-care activities as a consequence of this particular belief. This belief seemed to reinforce perceived burden in some of the caregivers in this sample.

Another belief, expressed by some of the caregivers in this sample, is the assumption that God is in full control of their lives. This belief, in some instances, was extrapolated to mean that God either caused or allowed dementia to come to their loved one which resulted in feeling of unjustly punished. This belief was manifest in the perceived relationship with God or a higher power which was discussed previously.

Feeling guilty for not living up to moral standards was another subtheme. One caregiver said: “when I’m really impatient. Of course it frustrates me because I don’t think it’s an appropriate, healthy spiritual response.” Another shared: “I always thought of myself as a patient person. I realize I’m not a patient person. Maybe I have a great deal of patience, but there is a great deal more patience I could have.”

6. Discussion

The current study builds on previous research on spiritual struggles, in the context of challenging life circumstances, to capture the lived experience of family caregivers of PWD in the early stages of disease progression. Major themes for spiritual struggles in our sample fell under the categories of transpersonal, interpersonal, and intrapersonal struggles and the corresponding subthemes that are noted in our findings. Several observations are provided in this discussion that weaves our findings together for a fuller understanding of spiritual struggles among caregivers of PWD in the early stages of disease progression.

The caregivers in this sample did not explicitly endorse having “spiritual struggles” when asked directly. However, their narratives were filled with examples of experiences, thoughts, feelings, and behavioral manifestations consistent with the conceptualization of spiritual struggles. This pattern is consistent with non-caregiver populations who have experienced trauma or difficult life circumstances (Exline et al. 2012). Perhaps there is not a common language for expressing this aspect of the self [spiritual struggles] in our society, or there is stigma associated with admitting or sharing about these concerns with others. These issues appear to be consistent with dualistic or reductionistic conceptualizations of human beings rather than holistic or integrated understandings of personhood.

Some of the caregivers in the current study experienced a crisis of meaning, stemming from spiritual struggles, consistent with non-caregiver populations (Desai and Pargament 2015; Mahoney et al. 2003). A crisis in meaning, in this sample, appeared to manifest most fully when the caregiving experience was: (1) viewed as negative or burdensome (e.g., overwhelming or unfair); (2) brought about as a means of punishment or testing from

God or a higher power; (3) the caregiver viewed dementia as desecrating what they held most sacred in their lives (e.g., their loved one); and (4) there was a lack of support or understanding from their spiritual or religious community.

Findings from this study expand upon the work in non-caregiver samples that document changes in spiritual functioning in response to violations of one's assumptive world (Pargament et al. 2005a; Warner et al. 2009). Among some persons with a Christian worldview, the perception of God's authority may be comforting. Caregivers, like other persons, may believe that God loves them and is in control of their lives. Therefore, they believe they should receive blessings. When life altering experiences arise, persons are often forced to reconcile previously held assumptions with the realities in their lives which can then lead to spiritual struggles.

Many caregivers in the current study viewed God or their higher power as benevolent and merciful prior to their loved one's diagnosis. Those who experienced emotions such as anger and doubt about God's benevolent nature tended to experience shame for having these emotions similar to non-caregiver populations (Froese and Bader 2010). Specifically some grappled with the possibility that God is more authoritarian and punitive than previously thought—and wondered what they or their loved one could have done wrong to deserve dementia.

In the literature, non-caregiver samples either resolve crises of meaning or faith in the context of stress and trauma by either adjusting their worldview to exclude or replace previously held beliefs that no longer fit with their lived experiences or overriding the difficult experience and continuing to hold fast to the initial belief(s) (Kevern and Stifoss-Hanssen 2020). In this sample, some caregivers felt that they had resolved their initial spiritual struggle(s) by concluding that regardless of their current caregiving experience, God would somehow use caregiving for their ultimate good.

In contrast, some caregivers in this study had not yet resolved whether to maintain or shift from pre-caregiving beliefs. However, none of the caregivers in this study reported having completely moved away from or replaced pre-caregiving beliefs or worldviews. Of note, the caregivers in this study were in the early part of the caregiving journey. With disease progression, it is possible that some caregivers could temporarily or permanently shift away from previously held spiritual beliefs in accordance with their lived experiences.

Non-caregiver samples experiencing crises of meaning based on difficult life circumstances or trauma may disengage with their faith communities or spiritual practices (Desai and Pargament 2015). While the current study yielded similar findings, another reason for disengaging from faith communities on the part of caregivers had to do with limitations brought on by the demands of caregiving (e.g., time, travel, etc.) rather than a specific spiritual struggle (e.g., feelings of shame stemming from being ignored, unwelcomed or unaccommodated by faith communities). This pattern echoes previous research with this population (Garrison 2021; Plunkett and Chen 2016).

7. Recommendations

Below we provide recommendations for professional practice with caregivers of PWD, faith-based congregations and researchers interested in building on this research:

7.1. Recommendations for Professional Practice

It may be tempting for those serving family caregivers to sidestep the spiritual aspects of caregiving, including spiritual struggles, and focus only on the psychological, social and physiological aspects of this life experience. However, overlooking spirituality, in our clinical experience and based on the current study, may fail to address a vital aspect of caregiving. The following recommendations for professional practice follow:

- (1) It is important for professionals serving family caregivers of PWD to recognize that caregivers do indeed experience spiritual struggles in response to their lived experiences of caregiving. Spiritual struggles are not unusual in this population and come in a variety of forms. There may be more than one specific struggle a caregiver is

- working through at any given time. The struggle(s) may be ongoing or resolve only to reemerge as a response to changes or challenges in the caregiving situation.
- (2) Spiritual struggles should not be pathologized but viewed as potentially natural responses to the lived experience of caregiving for a loved one with dementia. Open and nonjudgmental dialogue is vital when professionals are interacting with caregivers of PWD expressing these deep concerns.
 - (3) Spiritual struggles may occur whether or not an individual caregiver is a member of a religious or spiritual group. This factor remains a possibility for caregivers who identify as agnostic or atheist even though persons in these categories were underrepresented in our sample. For example, an atheist may experience a profound existential crisis in the context of caregiving—and although not specifically perceived as spiritual—touches the core of their being.
 - (4) Listening to and responding with compassion to caregivers' emotional reactions, such as possible anger with God, a higher power or a sense of alienation from a faith-based congregation, is imperative. In the current study, the perception of being discounted or stigmatized by religious leaders and congregations was present. These painful experiences for PWD and their family caregivers should be acknowledged, allowed full expression with potential advocacy as a possible response.
 - (5) Integrating routine spiritually-integrated assessment tools into professional practice for the purposes of identifying spiritual struggles as well as coping resources should be included in routine care for caregivers of PWD (McGee et al. 2021a). Semi-structured interview questions similar to the DCI (McGee et al. 2013) or self-report measures such as the Brief Religious Coping Inventory (RCOPE; Pargament et al. 2011) among other tools could serve as resources for assessment. However, we dissuade professionals from labeling any caregiver responses as positive or negative. Instead each caregiver's expressions should be validated, acknowledged with loving kindness and respect and explored for meaning.
 - (6) Self-care in general and spiritual self-care in specific should be promoted among caregivers of PWD. Based on our findings, caregivers may experience feelings of shame and guilt in regards to self-care which may be, in part, due to long-term religious beliefs that may be inadvertently reinforced by members of faith-based communities. Modes of spiritual self-care can range from participating in contemplative practices (e.g., centering prayer, mindfulness meditation, labyrinth walking etc.) to receiving healing prayer and support from the spiritual community to taking time to reflect in nature. Spiritual self-care may also include more religiously oriented activities such as church attendance, singing and listening to hymns and other religious music, spending time reading Scripture or other religious writing, attending worship services and remaining involved with one's community of faith. Spiritual care needs are diverse and unique to each caregiver.
 - (7) Involving PWD as well as their family caregivers in counseling may be beneficial (Gitlin and Hodddson 2015). PWD, especially in the early stages, should be included in conversations with caregivers around spirituality and meaning (McGee et al. 2021b). Facilitating spiritual conversations with both PWD and caregivers can potentially engage families in meaningful ways that will leverage their capacities for spiritual coping and growth as well as willingness to discuss together concerns such as end of life care.
 - (8) Additional training may be necessary to listen for and acknowledge the possibility of spiritual struggles in this population. Thus, we are proponents for training programs seeking to train professionals to ethically integrate of faith into practice.

7.2. Recommendations for Faith-Based Congregations and Spiritually Focused Organizations

Two primary recommendations for faith-based congregations and spiritually focused organizations are provided based on this study.

- (1) It is important to increase awareness in religious and spiritual communities of the realities and challenges family caregivers of PWD may face in a systemic way so compassionate responses can be provided. Awareness campaigns should not only include medical and psychological facts about dementia but also emphasize the personhood of PWD and ways for validating and tapping into the strengths of PWD and caregivers. Continued engagement in the spiritual community is vital for empowering PWD and their caregivers and reducing a sense of loneliness, isolation or despair.
- (2) Creative ways to implement accessibility to religious and spiritual activities is imperative as seen in this study. Congregations should consider virtual options and more individualized experiences, such as small groups, based on the lived experience of PWD and their caregivers.

7.3. Recommendations for Future Research

This line of research is ripe with possibilities that could potentially impact the lives of caregivers of PWD in a positive manner.

- (1) A next step, we believe, is to explore spiritual struggles among caregivers of PWD from a longitudinal perspective from initial diagnosis throughout the progression of dementia. It is possible that distinct forms of spiritual struggle may emerge at different points along the disease trajectory (e.g., by stage) with variations according to the form of dementia (e.g., Alzheimer's disease, vascular dementia, frontotemporal dementia etc.).
- (2) Likewise, there are unique subgroups of caregivers of PWD whom may have different perspectives on their lived experiences (e.g., spousal CGs as compared to adult children; caregivers with various religious or spiritual orientations; caregivers from diverse racial, ethnic and cultural backgrounds etc.). An understanding of the evolution of spiritual struggles and spiritual coping patterns in unique subgroups of caregivers may provide the insight needed to develop more nuanced resources and services.
- (3) In addition to gaining further understanding into the spiritual struggles that may manifest for caregivers, we recommend additional research on spiritual coping in this population. A balanced understanding of resources and struggles is important for moving forward to best supporting this population.

8. Limitations

There are several notable limitations to this study. First, non-probability sampling was utilized given the exploratory nature of this qualitative study. The results from this sample of convenience, therefore, should not be generalized to all caregivers of persons living with dementia. Second, participants were recruited by professional organizations serving persons with dementia and their family caregivers. Thus, persons who were not receiving formal care were not included, which may have left out underserved caregivers. Third, it was made explicit that the study was about the role of spirituality and positive psychological factors in PWD and their family caregivers. Persons who were not interested in this topic may have decided not to contact the researchers to learn more about the study. Fourth, the majority of studies conducted in this line of research in the United States have been with Christian populations. The current study is no different. Thus, findings cannot be generalized to people from other religions, spiritual orientations, or life philosophies. Likewise, although there are documented similarities in beliefs and practices among the three historical branches of Christianity (e.g., Orthodox, Catholic and Protestant), there may be between group differences in how caregivers process their lived experience. There are also differences in beliefs and practices among the various denominations or sects from these three branches. Finally, most participants in this study self-identified as female, cis-gendered, white persons with European ancestry who were college educated and born and raised in the United States. Additional research is warranted among diverse caregivers. For example, there is little research to date on caregivers who have been historically marginalized in the United States and around the World such as gender non-

conforming, non-binary or gender queer caregivers. First Nation or indigenous caregivers (e.g., Native American and Alaska Native Nations in the United States), black caregivers in the United States of African or Caribbean descent, persons from Latin American ancestry, Asian American caregivers, persons with Middle-Eastern ancestry and recent immigrants to the United States among others have had limited representation in caregiver studies, even though each of these groups are culturally unique.

9. Conclusions

Based on anecdotal professional practice, the lived experience of family caregivers of PWD may influence their spirituality and faith. Likewise, caregivers' spiritual or religious orientation(s) may influence their perceptions of the caregiving experience. A generally positive synergy among spirituality and the experience of caregivers have been reported in the research literature. However, little research has been conducted on the interactions among these factors which could lead to the experience of spiritual struggle(s).

In the current qualitative study, spiritual struggles were explored in depth among caregivers of PWD in the early stages of disease progression using a phenomenological approach. Spiritual struggles were not uncommon among the narratives of the family caregivers who participated in this study. We believe that spiritual struggles are not negative in and of themselves but may be on the continuum of normative response(s) to the emotionally painful and overwhelming life circumstances that caregivers and their loved ones diagnosed with dementia may face.

The experience of spiritual struggles may also be a facet of spiritual coping among caregivers of PWD and natural circumstances in which some caregivers contemplate the deeply spiritual questions of personhood, meaning in life, disease and dis-ease, the dying process, death and mortality. An opportunity to live into and potentially transform suffering may occur when caregivers and their loved ones with dementia engage in heart-centered dialogue with their spiritual leaders, counselors, or other persons who can be fully present without judgment.

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