

Article

Does the Tough Stuff Make Us Stronger? Spiritual Coping in Family Caregivers of Persons with Early-Stage Dementia

Jocelyn Shealy McGee ^{1,*} , Morgan Davie ¹, Rebecca Meraz ², Dennis Myers ¹
and Stephanie Clintonia Boddie ^{1,3,4,5} 

¹ Garland School of Social Work, Baylor University, Waco, TX 76701, USA

² Louise Herrington School of Nursing, Baylor University, Dallas, TX 75246, USA

³ George W. Truett Theological Seminary, Baylor University, Waco, TX 76706, USA

⁴ School of Education, Baylor University, Waco, TX 76798, USA

⁵ Institute for Gender Studies, College of Human Sciences, University of South Africa, Pretoria 0003, South Africa

* Correspondence: jocelyn_mcgee@baylor.edu

Abstract: Spiritual coping may be conceptualized as relying upon spiritual beliefs, practices and/or relationships as an aspect of navigating stressful or traumatic experiences. There is evidence that spirituality may be used as a resource and may cultivate growth for some in the midst of difficult life circumstances. There is limited research, however, on this phenomenon among family caregivers of persons living with a dementia, particularly those in the early stages. The purpose of the current study, therefore, was to gain insight into the nature of spiritual coping among caregivers of persons living with a dementia in the early part of their caregiving journey. Using interpretative phenomenological analysis, interviews with 28 caregivers were analyzed. Five spiritual coping themes and corresponding subthemes emerged from their narratives: (1) spiritual relational coping; (2) spiritual behavioral coping; (3) spiritual belief coping; (4) spiritual coping to gain a sense of control; and (5) spiritual coping for constancy or life transformation. Three-fourths of the sampled caregivers reported growth in their spiritual lives during the early part of their caregiving journey. A sense of being “spiritually grounded” in the Divine (e.g., God, a higher power, a life philosophy) and oneself (as a spiritual being) was an important aspect of spiritual coping in this sample. Additionally, caregivers tended to use multiple forms of spiritual coping simultaneously while also navigating spiritual struggles. Finally, some caregivers viewed caregiving as a spiritual path that they were actively following rather than a passive spiritual experience. These findings speak to the importance of identifying and encouraging spiritual coping among caregivers as well as identifying spiritual struggles.

Keywords: dementia; caregiving; spiritual; religious; coping; growth



Citation: McGee, Jocelyn Shealy, Morgan Davie, Rebecca Meraz, Dennis Myers, and Stephanie Clintonia Boddie. 2022. Does the Tough Stuff Make Us Stronger? Spiritual Coping in Family Caregivers of Persons with Early-Stage Dementia. *Religions* 13: 756. <https://doi.org/10.3390/rel13080756>

Academic Editors: Suvi-Maria Saarelainen and Nigel King

Received: 18 July 2022

Accepted: 10 August 2022

Published: 19 August 2022

Publisher's Note: MDPI stays neutral with regard to jurisdictional claims in published maps and institutional affiliations.



Copyright: © 2022 by the authors. Licensee MDPI, Basel, Switzerland. This article is an open access article distributed under the terms and conditions of the Creative Commons Attribution (CC BY) license (<https://creativecommons.org/licenses/by/4.0/>).

1. Introduction

Jane, a 71-year-old retired teacher, was diagnosed with Alzheimer's disease a little over a year ago. The first signs were difficulty remembering conversations, which she thought was related to changes in hearing. Later, she noticed that she was having trouble remembering well-known recipes and kept forgetting to turn off the burner after cooking. She and her husband William were married a little over 50 years when she received this diagnosis. The couple were provided with information on how the disease would likely impact them over time by a neurologist. William pondered how smart and engaging Jane was and wondered how he could possibly cope with being her caregiver if the symptoms of the disease progressed. Looking for support, the couple reached out to members of their Bible study group at church. The Bible study group let William and Jane know they were praying for them and recommended that they read the Bible verse Psalm 23: “Even though I walk through the valley of the shadow of death, I

will fear no evil, for you are with me; your rod and your staff, they comfort me". Other church members offered to help cook meals and do other tasks as needed. On particularly difficult days, William prayed for a renewal of his strength. He drew comfort by reminding himself that "in all things God works for the good of those who love him". (Romans 8:28, ESV). He wondered, "Does the tough stuff really make us stronger?" when contemplating he and Jane's lived experience.

We begin this article with the above illustrative account of a family's use of several spiritual coping strategies in response to their experiences living with a dementia in the early stages of disease progression. This account is a compilation of narratives from clinical practice rather than representing a specific family. As you can see, families may tap deeply into their spiritual roots to help them live well with a dementia. In this account, William and Jane seek out support from their community of faith, receive prayers and meals from the community, and derive comfort from reading Scripture that supports their beliefs about their higher power (e.g., God).

There is an emerging body of research on the role of spiritual coping among caregivers of persons living with a dementia (Giannouli and Giannoulis 2020). However, spiritual coping among this distinct population has not been fully explored. Even less research has been focused on family caregivers of persons living with a dementia in the early stages (McGee et al. 2021b, 2022). Additionally, a review of the literature indicates that many studies on spiritual coping among caregivers have been quantitative. The purpose of the current qualitative study, therefore, was to gain a deeper understanding of this phenomena using interpretative phenomenological analysis (IPA) of caregiver narratives.

Before we delve into relevant background information for this article, it is important to note that we are not referring to spiritual coping in a theological sense or trying to determine ultimate truth from a religious viewpoint. We are instead approaching the construct of spiritual coping through a psychological lens and examining the perceptions of caregivers in a specific sample. Additionally, persons from many faith traditions, spiritualities and life philosophies may utilize spiritual coping strategies even though the illustrative account in this article comes from a Christian perspective. Finally, we are conceptualizing spiritual coping broadly and subsuming beliefs and practices associated with religion within the larger construct of spirituality.

2. Background

2.1. Dementia and Family Caregiving

Alzheimer's disease, which is classified as a dementia, is a progressive and terminal disease. Unpaid, informal caregivers—most of whom are family members—provide the majority of care needed by loved ones who have been diagnosed with a dementia. It is estimated that approximately 26% of persons in the United States were caring for someone with Alzheimer's disease or another dementia in 2020 and this number is rising (National Alliance for Caregiving 2020). The caregiving experience appears to be ubiquitous, as reflected by former USA First Lady Rosalynn Carter, "I like to say that there are only four kinds of people in the world—those who are currently caregivers, those who will be caregivers and those who will need caregivers" (The Carter Center 2011).

The care needs of persons with a dementia can change quickly and are not always predictable (National Institute on Aging 2022). Caregivers must constantly adjust and readjust to the relational dynamics with their loved ones as the dementia progresses (Bons-Storm 2016). Caregivers of persons with a dementia tend to report higher levels of distress when compared with caregivers of persons with other chronic illnesses (Lloyd 2013). They are faced with learning how to balance the evolving care needs of their loved one while maintaining their role as family member or friend (Lloyd 2013).

Stressors from caregiving responsibilities can accumulate and may develop into the perception of caregiver burden (Kezirian 2019). Perceptions of caregiver burden can influence multiple areas of a caregiver's functioning, including but not limited to, physical and mental health, employment opportunities, financial standing and relationships outside of caregiving

(Hughes et al. 2014; Riffin et al. 2017; Kezirian 2019). Caregivers whose loved ones are in the beginning stages of a dementia are a unique subset of caregivers and some may experience strong emotions such as fear, disbelief, shame and anger (Bons-Storm 2016).

2.2. Coping and Perceived Control

Perceived control (primary and secondary), in light of biopsychosocial demands and personal resources, is a key factor in the interpretation of difficult life experiences (Arntz and Schmidt 1989). Primary control is built on an individual's ability to change a situation directly to better fit the needs of the self, while secondary control grows out of accepting one's lack of primary control and seeking control outside of the self (Rothbaum et al. 1982). Those seeking secondary control may ask for assistance from their spiritual communities (vicarious control), believe in fate or a divine plan (illusory control), create an acceptable or positive interpretation of the situation (interpretive control), or try to anticipate future events (predictive control) (Rothbaum et al. 1982). Coping through spirituality may provide the means for primary and secondary forms of control (Pargament 1997, 2007).

2.3. Religious and Spiritual Coping

The most extensive body of research on religious and spiritual coping has grown from Pargament's seminal work (Pargament 1997) over the last three decades. Spirituality, according to Pargament, is a "search for the sacred" (Pargament 2007, p. 32) and should not be minimized or "explained away" (Pargament 2007, p. 31). Coping through spirituality may be defined as "a search for significance in times of stress" (Pargament 2007, p. 90).

Spiritual coping may be classified as positive or negative (e.g., less effective) depending on the impact the coping has on a person (Pargament 1997). Examples of positive spiritual coping are reframing stressors as salutary, treating the Divine as a partner and/or seeking and appreciating the love and care of a higher power (Pargament 2011). It can also manifest in believing that one's relationship with the Divine is secure amidst stressors, feeling a sense of spiritual connection with others and seeing the world as generally benevolent. There are also spiritual coping strategies which have been identified as less effective among Judeo-Christian samples such as treating a stressor as punishment from God or passively relying on God to resolve the stressor (without taking any personal action) (Pargament 2011). However, these are also ways to make sense of life circumstances and may be bound to unique religious or cultural teachings and beliefs.

There are at least five functions of spiritual coping according to Pargament et al. (2013) including finding meaning in the midst of life's valleys, gaining a sense of control, acquiring comfort by virtue of one's perceived closeness to God or a higher power, achieving closeness with others and transforming life. Persons may use relational, behavioral and belief strategies that rely on religious belief systems to facilitate their adjustment to or alleviate the stress (Pargament et al. 2013; Tomás and Rosa 2021).

2.4. Research on Spiritual Coping among Caregivers

The majority of studies on spiritual coping among caregivers have been conducted with Judeo-Christian samples. Personal spirituality has been identified as a generally positive factor (Giannouli and Giannoulis 2020; Kevern and Stifoss-Hanssen 2020). The Family Caregiver Alliance posits that spiritual coping is one of the most important coping strategies for caregivers (Family Caregiver Alliance [FCA] 2016). The use of certain spiritual coping methods among caregivers has been associated with improved mental health, well-being, distress management, a sense of caregiving efficacy and less perceived burden (Damianakis et al. 2018; Heo and Koeske 2013; Kazmer et al. 2018; Lloyd 2013; Saffari and Chen 2019; Salamizadeh et al. 2017).

There is also evidence that various spiritual coping methods may serve as a protective factor for some caregivers against negative physical health outcomes (Mahdavi et al. 2017). Receiving social support, experiencing a sense of community, maintaining a relationship

with a higher power and deriving meaning are some of the possible benefits of spiritual coping among caregivers (Fife et al. 2020).

2.5. *Spiritual Relational Coping among Caregivers*

For non-caregivers, viewing one's relationship with a the Divine as positive and supportive is a powerful form of spiritual coping (Pargament 2007). Caregivers who spend time connecting with their higher power and have more positive appraisals of caregiving tend to be at lower risk for depression, have better health outcomes and a lower level of perceived caregiver burden (Lloyd 2013; Shin et al. 2017). Faith or spiritual communities may also provide family caregivers opportunities for social engagement and relational emotional support (Agli et al. 2015; Giannouli and Giannoulis 2020). These opportunities may serve as buffers for stress, anxiety and depression (Damianakis et al. 2018; Li et al. 2012).

2.6. *Coping with Caregiving through Engaging in Spiritual Practices*

There is evidence that caregivers can benefit from engaging in various spiritual practices. For example, prayer, attending Bible study and other events, listening to religious or spiritual programs and reading Scripture and other religiously oriented material may be beneficial for some (Bull 2013; McGee et al. 2022; Giannouli and Giannoulis 2020). Contemplative practices, such as centering prayer, mindfulness and other forms of meditation may decrease stress and improve quality of life (Brown et al. 2015; Waelde et al. 2017). There is also evidence that caregiver levels of engagement with spiritual practices tend to increase from pre-caregiving levels (Kaye and Robinson 1994).

2.7. *Using Spiritual Beliefs for Coping with Caregiving*

Tapping into spiritual beliefs for coping and finding meaning in the context of caregiving is not unusual. How a difficult circumstance is appraised for meaning, including caregiving, may significantly impact perceptions of stress (Nowlan et al. 2015). There are several ways that caregivers may make meaning in the context of caregiving (Kevern and Stifoss-Hanssen 2020). Relating back to the concept of secondary control, caregivers may build illusory control through the belief that God has a plan for their lives even when their current circumstances are difficult (Shim 2020; Stuckey 2001). Some caregivers may build interpretive control if they believe that dementia was allowed by God to gift them with a greater purpose (Lloyd 2013). In this way, a caregiver may engage in predictive control through a belief that the Divine will work everything out for their growth and benefit.

3. Methods

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

3.1. *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) person with dementia is within 2 years of a dementia diagnosis; (c) over the age of 21; (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.

3.2. *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 mostly Caucasian (92.9%). Education status was high, with many participants having earned 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). There was one participant who identified as a Spiritualist and one as Agnostic.

3.3. Recruitment

Participants were recruited from a medical school and other community agencies who serve persons with dementia 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 influence the lives of persons with dementia and their family members. Those who were interested in participating 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 for interested and eligible persons.

3.4. Instrument

After the consent 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.).

3.5. 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.

3.6. Design and Data Analysis

To gain a deeper understanding of spiritual coping strategies among family caregivers of persons with dementia, interpretative phenomenological analysis (IPA) of the semi-structured interviews was utilized. The advantage of an IPA design was the opportunity to examine the inner-most deliberations of participants and make interpretations of the meaning of their lived experiences (Alase 2017; Smith et al. 2009). 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 et al. (2009) were utilized for analyzing the interviews. Four members of the research team first 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 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 essence of participants’ lived experiences. Next, the team interpreted the data to develop themes for spiritual coping and caregiving. 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 and Creswell 2018; Merriam 2002). Additionally, the data from the interviews, observations and field notes were triangulated to provide contextual accuracy.

4. Findings

Findings from this study are organized according to five major themes: (1) spiritual relational coping; (2) spiritual behavioral coping; (3) spiritual belief coping; (4) religious and spiritual coping to gain a sense of control and (5) spiritual coping for constancy or life transformation. Subthemes for each theme described below in detail.

4.1. Religious and Spiritual Relational Coping

The first major theme observed in the narratives of the caregivers in this study was spiritual relational coping. Subthemes were: (1) seeking comfort from the Divine; (2) seeking guidance from the Divine; and (3) being “spiritually grounded” through a relationship with the Divine. These subthemes are described below with examples from caregivers’ narratives.

4.1.1. Seeking Comfort from the Divine

The caregivers in this study shared about the importance of spending quality time with the Divine which could be a higher power or the self as spiritual being. A central reason for doing so was to renew strength and motivation in the context of caregiving. For example, one caregiver explained, “I kind of talk to Him [God] during the day when things get stressful”. Another caregiver stated that she felt comforted by a poignant metaphor, “we live in the amniotic fluid of God. In the womb of God, floating in that amniotic fluid, is that not a wonderful thing?” This statement conveyed a sense of nurturance and rest for this caregiver in her relationship with the Divine.

4.1.2. Seeking Guidance from the Divine

Similar to seeking comfort from the Divine, some caregivers engaged in relationship with the Divine for guidance on how best to care for their loved ones. These caregivers sought out their higher power when they did not know how to make a caregiving decision or when they needed encouragement to continue. For example, one caregiver described the importance of seeking guidance from the Divine in their life this way: “There is a spirit that leads you and if you listened, if you would be still and know that I am God, you can get the message [what to do for each emerging circumstance]”. Another caregiver described their engagement with the Divine as an ongoing prayer “for guidance”.

4.1.3. Being Spiritually Grounded through a Relationship with the Divine

The theme of being “spiritually grounded” through prioritizing the relationship with the Divine emerged in this sample. For some caregivers, the Divine pertained to their connection with God or a higher power. For others, the Divine pertained to a connection with their “higher self”. Prioritizing this connection led to perceptions of being better able to care for a loved one with dementia for some participants. For example, one caregiver explained this phenomenon as, “my relationship with God comes first and when that is mature or grounded, then I am able to move out and take care of other people [including my loved one]”. Another caregiver explained the same concept a different way, “I feel like I

know who I am and how I'm grounded in my being [spirit] . . . and I can tend to whatever is around me because of that or tend to it better".

4.2. *Spiritual Behavioral Coping*

The second major theme observed in the narratives of the caregivers in this study was spiritual behavioral coping. Subthemes were: (1) seeking support from the spiritual community; (2) spiritually oriented behaviors for religious helping; (3) spiritually oriented behaviors for gaining intimacy; (4) spiritually oriented behaviors to solidify a sense of purpose; and (5) Spiritual coping to gain intimacy with the self. These subthemes are described below with examples from caregivers' narratives.

4.2.1. Seeking Support from the Spiritual Community

Most participants in this sample were actively involved with a spiritual community before their loved one was diagnosed with a dementia. Support from their spiritual communities occurred spontaneously or in response to direct requests from the caregiver or the person with dementia. Prayer was the most often reported behavior that their spiritual communities provided for the caregivers and their loved ones, "They [the church] help because they know what I'm going through with my dad. They pray".

Tangible care to meet specific needs was also provided: "People [from church] have welcomed my mother into their homes [when I needed to run errands]" one participant explained. Another shared: "Our church, helps with transportation and meals". Another caregiver said, "People stop by to see my mother [at her assisted living residence] and always warmly welcome her, treat her very kindly [when at church]". Still another caregiver stated, "They [the church leaders] provided money for us to move my mother into assisted living".

4.2.2. Caregivers Spiritually Oriented Behaviors for Religious Helping

The caregivers in this sample shared that helping other people or volunteering in the community was spiritually meaningful to them. Likewise, it was spiritually meaningful to their loved one with a dementia. For example, one caregiver explained, "We [the caregiver and the person with dementia] do healing work on individuals and the planet, and we have traveled . . . to sacred sites all over the world over the last twenty-five years and done energy work on those specific places". Other caregivers engaged in volunteer work such as Meals-on-Wheels or volunteered at their local animal shelter. These caregivers viewed this volunteer work as a spiritual practice that provided them with opportunities to demonstrate loving kindness, compassion and connections with other people.

4.2.3. Spiritually Oriented Behaviors for Gaining Intimacy

In this sample, caregivers who engaged in spiritual practices with their loved ones before receiving a dementia diagnosis tended to continue these practices after the diagnosis. A central aspect of this form of spiritual coping was for maintaining intimacy and solidarity between the caregiver and their loved one with dementia. For example, one caregiver stated, "we go to church every week, it's a big part of our lives, we're both active in the Catholic church. It means a lot to us to still do this".

4.2.4. Spiritually Oriented Behaviors to Solidify Sense of Purpose

Other caregivers considered caregiving to be part of their overall purpose and thus their spirituality. For example, a caregiver explained the importance of her caregiving role this way, "I feel a stronger obligation to take my mom to church now that I have her and [nephew]. Because now I'm that person who gets them to church". This caregiver went on to say that this aspect of her role gave her a sense of purpose.

4.2.5. Spiritual Coping to Gain Intimacy with the Self

Spiritual coping to strengthen a connection to the self largely revolved around contemplative practices. Meditating and being in nature were frequently mentioned contemplative practices. For example, a caregiver explained, “I find my peace out there with the birds or the squirrels. I wouldn’t have survived the last two months without my backyard”. Another caregiver expressed their process of connection with herself as, “I’m very much attuned to my [spiritual] integration, my having things together, sense of priorities”.

4.3. Spiritual Belief Coping

The third major theme observed in the narratives of the caregivers in this study was coping through spiritual beliefs. Subthemes were: (1) engaging with spiritual or religious readings; (2) benevolent spiritual reappraisal of the caregiving experience; and (3) reappraising the power of God or the Divine in a positive manner in the context of caregiving. These subthemes are described below with examples from caregivers’ narratives.

4.3.1. Engagement with Spiritual or Religious Readings

Some of the caregivers in this study utilized scripture and other spiritual readings to find comfort or guidance within the context of caregiving. Most of the teachings that the caregivers in this sample believed were relevant to their circumstances were focused upon overcoming trials and tribulations. For example, one caregiver found comfort by framing their lived experience as a time of “testing” that could lead to spiritual development:

We’re told we’re going to be tested. You’re not gonna know why but there’s a lot of them. You’re going to go through some dark times. You’re gonna . . . but at the end of that: bright light. Wait for the light to come back on, and get through the dark part.

Other caregivers looked to spiritual texts for practical guidance. For example, a caregiver explained, “When you look at the Old Testament, the instructions in Psalms God’s given to the Israelites about family and sacrifice. There will be reward later”. Another caregiver found the phrase “Be Not Afraid” repeated in Judeo-Christian scriptures as a guiding principle for caregiving.

When asked about spiritual teachings or readings, some caregivers explained that they felt a sense of connection with the Biblical characters. For example, one caregiver compared themselves with the Job, stating, “Job, he keeps saying ‘I didn’t do anything wrong,’ . . . [my husband] nor I had done anything to bring this dementia on us”. Another compared their experience with Joseph, explaining, “[Joseph] was, you know his brothers sold him into Egypt and he could have thought that that was a terrible thing, but then when there was famine in the country, and you know it brought positive aspects to it”. These caregivers looked to Biblical characters experiencing trials and tribulations to assign meaning to their own lived experience and found some comfort in the idea that the experience of suffering was part of being a person. In other words, they were not alone.

4.3.2. Benevolent Spiritual Reappraisal of the Caregiving Experience

Another subtheme was benevolent spiritual reappraisals of the caregiving experience. For example, the belief that God is in control was comforting for some participants: “I know he’s looking out for me and I know He’s in control”. Other caregivers interpreted their lived experience as something that would ultimately bring about good. For example, a caregiver shared, “God is love and whatever is transpiring, He has a plan. I can’t see it, but He knows the greater good”. A caregiver shared that he found encouragement in the belief, “I will not, I haven’t been given anything I can’t handle”. Another caregiver shared a similar sentiment, “I know that being a caregiver, I would have never ended up in that position if God didn’t know that I could do it”.

4.3.3. Reappraising the Power of God in a Positive Manner in the Context of Caregiving

Another subtheme was positive reappraisal of God's power in the context of caregiving. For example, one caregiver stated, "coming from there to now I found the strength I didn't think I had. Like I said, God did it for me". Other caregivers attributed their present coping with caregiving to God's power. As one caregiver described, "God is indwelling in me and you know that's something that came before I was doing caregiving. Thankfully. Because if that hadn't been in place when [loved one] was diagnosed, I'd probably be a basket case".

4.4. Religious and Spiritual Coping to Gain Control

A fourth major theme emerging from this study was using religious or spiritual coping to gain a sense of control, whether it be primary or secondary control. This theme was related to the question, "who has control over my caregiving experience?" as shared by one caregiver. Subthemes were: (1) collaborative coping with the Divine; (2) active spiritual surrender or giving one's circumstances over to God; (3) passive spiritual deferral and (4) spiritual coping for the purposes of constancy or life transformation. These subthemes are described below with examples from caregivers' narratives.

4.4.1. Collaborative Coping with the Divine

The subtheme of collaborative coping with the Divine was present in the narratives of the caregivers who participated in this study. This way of coping was manifest when caregivers believed that God or a Higher Power would provide for their needs and the needs of their loved while also actively maintaining their own caregiving efforts. One caregiver explained that although they believed God was in complete control of their situation, "It doesn't mean not to think and it doesn't mean don't try, but it means to recognize that this is towards His goal".

Some caregivers achieved a sense of control through collaborative coping with the Divine by beseeching God to provide them with the positive attributes necessary for caregiving, such as patience, love, or strength. One caregiver described their caregiving prayer, "Give me strength, give me wisdom, patience. Give me love. Give me understanding". Other caregivers asked the Divine to guide them as they managed caregiving and felt a sense of empowerment by their Higher Power. An example was the belief shared by one caregiver, "I can do all things through Christ who strengthens me" which suggests that this caregiver viewed the Divine as his partner in caregiving. Another caregiver stated, "I find strength in prayer and in God".

4.4.2. Active Spiritual Surrender or Giving the Circumstances over to God

The subtheme of giving one's circumstance over to God or active spiritual surrender emerged from caregiver' narratives. This way of coping was manifest when a caregiver actively placed their circumstances in God's hands. Similar to collaborative spiritual coping, caregivers who expressed active spiritual surrender believed they had an active role to play in caregiving despite the belief in the Divine's ultimate control. For example, one caregiver explained, "I just think that the Lord is going to take care of us. Period. The end". This caregiver was, however, doing everything she could to assist her loved one with a dementia but also found comfort in the belief that God would make everything work out. Another caregiver shared a similar sentiment:

If I worry about the future, then I'm not going to be able to take care of myself and my family. So just take it one day at a time and be able to know that it is in His hands. Everything is in His hands.

4.4.3. Passive Spiritual Deferral

Distinct from active spiritual surrender, some caregivers engaged in passive spiritual deferral. This way of spiritual coping involves waiting for the Divine to change the situation. For example, one caregiver was relieved to give up on trying to discern God's will for his life. He stated, "If I was trying to figure out why this and that happened I would spend all

my time trying to figure out why everything happened". Another form of passive spiritual deferral had to do with denying having any control over the caregiving experience. For example, one caregiver explained, "When things are insurmountable, I turn it over to God. Uh, you know, just I can't get through this, you got to do it for me you know". Another caregiver described the total reliance on God financially as, "We are totally dependent on God because we are getting a little bit in from the government, but that ain't much". Another caregiver expressed passive deferral by asking God for miraculous healing of their loved one with dementia. This caregiver stated, "I always pray for a miracle. I just, maybe one day there will be a cure".

4.5. *Spiritual Coping for the Purposes of Constancy or Life Transformation*

A fifth major theme related to spiritual coping emerging in this study was obtaining spiritual constancy or life transformation. For example, some caregivers explained that the caregiving role was consistent with their pre-caregiving spiritual beliefs. For example, a caregiver said, "I think I've basically integrated this role into a process that has been happening for a while". When queried, the caregiver explained that the requirements of caregiving built upon their spiritual truths or beliefs which had remained consistent over time.

Another example of spiritual constancy and a strengthened spiritual connection with her higher power is evident in this quote: "Before I became a caregiver I was always dependent on him [God] . . . but since I became a caregiver I'm looking to him much more. I really do much more". Some caregivers expressed that their relationship with the Divine had deepened since becoming a caregiver. For example, one caregiver described changes to their relationship with God as, "there's more understanding of the value or relationship".

Still other caregivers shared that their spiritual beliefs had grown or transformed over the caregiving journey as they came to better understand "God's will" or trust in "God's plan". A spousal caregiver shared the words of the song to convey her truth about her own spiritual transformation through caregiving, "That song it's, 'through it all I've learned to trust in Jesus, through it all I've learned to depend upon his Word'. If you've never had a problem, you don't know what trust in God can do".

5. Discussion

The current study builds on previous research on spiritual coping among caregivers of persons living with a dementia (Kevern and Stifoss-Hanssen 2020) to capture their lived experiences in the early stages of disease progression. There were five overarching themes or mechanisms of spiritual coping that emerged from the study—spiritual relational coping, spiritual behavioral coping, spiritual belief coping, religious and spiritual coping to gain control and spiritual coping contributing to spiritual constancy, strengthening one's spirituality or spiritual transformation/growth. These themes were consistent with previous research on spiritual coping in other populations (Pargament et al. 2013).

The most predominant theme among the caregivers in this study was a desire to spend quality time and actively engage with the Divine. Similar to previous studies, this form of spiritual coping was connected to an improved sense of caregiver efficacy (Damianakis et al. 2018). A positively regarded relationship with the Divine was also suggestive of a lower sense of perceived burden in the current sample, which is consistent with findings from other studies (Giannouli and Giannoulis 2020; Saffari and Chen 2019). Specifically, caregivers who felt that they were spiritually grounded in themselves and in their relationship with the Divine expressed being able to better take care of themselves and their loved one with dementia.

Most of the caregivers in this study perceived their faith communities as being supportive and valued the time, attention and spiritual support received. Overall, our findings are consistent with previous research suggesting that social and tangible support from faith communities is an important element for coping with caregiving (Fife et al. 2020).

In the current study, we also identified that it is efficacious for caregivers to know that they too are contributors to their faith communities, the larger community and the greater good. While the literature discusses social support as an avenue for vicarious control (Rothbaum et al. 1982), which is more extrinsically motivated, the narratives of the caregivers in this study conveyed a sense of gratitude for their communities. Perhaps continuing to contribute to the well-being of the community may be a facilitator of spiritual resilience among caregivers and their loved ones with a dementia. A reciprocal relationship of giving and receiving, in this study, appeared to be integral for spiritual health among participants. Receiving and accepting support may serve as an encouragement to caregivers and can also be a catalyst for spiritual growth for the community.

Many of the caregivers in this study experienced spiritual struggles related to painful experiences with their faith communities such as feeling judged and stigmatized (McGee et al. 2022). Therefore, when working with caregivers, careful inquiry about the nature of their unique relationship with their faith community should take place. This type of inquiry may lead to opportunities for education, transformation, and healing in faith communities as well as among caregivers and their loved ones with a dementia. Various forms of spiritual struggles may occur simultaneously with unique ways of spiritual coping.

In support of Pargament's work, many of the spiritual coping themes observed in the current study could be framed as a "search for significance" in the context of caregiving through reappraisals of the situation. Caregivers in this study sought interpretations of their lived experiences that allowed for their spiritual beliefs and some of the difficult aspects of their caregiving experience to coexist. Our findings reiterate the central importance of caregivers' individual interpretations of their lived experience for coping outcomes (Lloyd 2013; Stuckey 2001).

Spiritual coping to gain a sense of primary or secondary control is central to persons coping with difficult life experiences. Persons with positive spiritual coping tend to rely not only on their own strength but also draw strength and other resources from the Divine to better care for themselves and those around them (Bons-Storm 2016; Pargament 2007). In this way, caregivers' collaboration with the Divine empowered them and increased their perceived primary control while drawing secondary control from the Divine (Rothbaum et al. 1982). Caregivers, as we observed in the current study, may also refrain from taking the initiative to change their condition and may rely solely on the Divine to change their situation, which is a more passive form of relational coping (Bons-Storm 2016; Pargament 2007).

The caregivers in this study tended to experience more spiritual growth when they employed collaborative coping with the Divine or active surrender, rather than passive religious deferral. This finding was consistent with other studies that highlight the benefits of collaborative spiritual coping (Bons-Storm 2016). Through collaborative or active surrender, caregivers may be able to bolster their perceived primary control through the belief that they will be given all the resources necessary to competently provide care for their loved one with a dementia.

Posttraumatic spiritual growth can be defined as finding acceptable interpretations of an experience, feeling empowered by beliefs, and feeling increased well-being in relationship with the Divine following traumatic or difficult life experiences (Pargament et al. 2000; Pargament 2002, 2011; Xu 2016). Consistent with previous studies (Fauziana et al. 2018; Netto et al. 2009) providing care for a loved one with dementia can bring about spiritual growth and transformation through an ongoing and evolving challenging life circumstance.

6. Recommendations

It is important for professionals to recognize that spirituality is an important aspect of personhood in caregivers of persons with early-stage dementia. Caregivers may utilize spirituality as a resource while simultaneously experiencing spiritual struggles (McGee et al. 2022). Some caregivers may consider caregiving to be a spiritual path in and of itself or as the embodiment of deeply held and valued spiritual beliefs. Professionals need to acknowledge the complex interplay between potential spiritual struggles

and spiritual coping responses, among caregivers, as well as their unique cultures and backgrounds. We would like to emphasize the importance of listening deeply without judgment to caregivers who experience spiritual struggles. A range of spiritual struggles as well as spiritual coping responses are likely normative and are certainly interconnected.

We recommend integrating spiritually oriented assessment tools into professional practice for the purposes of identifying the degree to which spirituality is important to a given caregiver, whether or not they are experiencing spiritual struggles and the unique constellation of their resources for spiritual coping (McGee et al. 2021a, 2022). 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. 2000) may serve as assessment resources. Additional research is needed in this area.

Based on the spiritual coping literature and our findings, we recommend that communities of faith and other organizations that emphasize spirituality seek to educate themselves about the challenges family caregivers of persons with a dementia may experience so that compassionate responses can be provided. Awareness campaigns should not only include medical and psychological facts about dementia but also emphasize the personhood of persons with a dementia and ways for validating and tapping into the strengths of persons with a dementia and their caregivers. As seen in this sample, caregivers can and do experience connection and enjoyment when engaging in spiritual coping with their loved one who has been diagnosed with a dementia. Both the caregiver and their loved one with a dementia should be included in communal practices when possible (McGee and Myers 2014).

It would be beneficial to study spiritual coping among caregivers of persons with a dementia from a longitudinal perspective from initial diagnosis throughout the progression of dementia. It is possible that distinct forms of spiritual coping and growth may emerge at different points along the disease trajectory (e.g., by stage) along with spiritual struggles. A longitudinal design could also explore potential health benefits and protective qualities of spiritual coping in caregivers. Likewise, variations in caregiver spiritual coping should be explored according to the form of dementia (e.g., Alzheimer's disease, vascular dementia, frontotemporal dementia).

There are many subgroups of caregivers of persons with a dementia who may have diverse perspectives on spiritual coping and unique needs and challenges. For example, there is little research to date on spiritual coping among caregivers who have been historically marginalized, subjected to colonization and living in underresourced countries. An understanding of the evolution of spiritual coping and spiritual growth patterns among unique subgroups of caregivers may provide the insight needed for the development of more nuanced resources.

7. Limitations

We outline 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 of persons with dementia. Third, it was made explicit that the study was about the role of spirituality and positive psychological factors in persons with dementia and their family caregivers. Persons who were not interested in this topic may have decided not to contact the researcher team 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, life philosophies or communities. Likewise, although there are documented similarities in beliefs and practices among the three historical branches of Christianity (e.g., Orthodox, Catholic, and Protestant), there are also significant between-group differences that may be reflected in how each individual caregiver processes 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.

8. Conclusions

Caregiving for someone with a dementia is an experience that many people will face at some point in their lives. This study provides a glimpse into spiritual coping among family caregivers for persons in the early stages of dementia. The majority of caregivers in the current study shared a diverse array of spiritual coping orientations as well as endorsing personal and spiritual growth in the context of caregiving. For some, the experience of caregiving may serve as a catalyst for deeper reliance upon their pre-caregiving spiritual beliefs and practices. For others, perceptions of positive caregiving was made possible by the strength and motivation that caregivers experienced by engaging in spirituality. For others, the experience of caregiving may serve as a time of spiritual transformation or growth.

Author Contributions: Conceptualization, J.S.M., M.D., R.M. and D.M.; methodology, J.S.M., M.D. and R.M.; formal analysis, J.S.M., M.D., R.M.; investigation, J.S.M.; resources, J.S.M.; data curation, J.S.M.; writing—original draft preparation, J.S.M., M.D., R.M., S.C.B.; writing—review and editing, J.S.M., M.D., R.M. and S.C.B.; supervision, J.S.M.; project administration, J.S.M. All authors have read and agreed to the published version of the manuscript.

Funding: This research received no external funding.

Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki, and approved by the Institutional Review Boards of Baylor University (protocol code #346183-1, date of approval: 8 July 2012) and Baylor College of Medicine (protocol code #H27755, date of approval: 20 July 2012).

Informed Consent Statement: Informed consent was obtained from all research participants involved in the study.

Data Availability Statement: The data presented in this study are not publicly available for the purposes of privacy and confidentiality of research participants.

Conflicts of Interest: The authors declare no conflict of interest.

References

- Agli, Oceane, Nathalie Bailly, and Claude Ferrand. 2015. Spirituality and religion in older adults with dementia: A systematic review. *International Psychogeriatrics* 27: 715–25. [CrossRef] [PubMed]
- Alase, Abayomi. 2017. The Interpretative Phenomenological Analysis (IPA): A guide to a good qualitative research approach. *International Journal of Education and Literacy Studies* 5: 9–19. [CrossRef]
- Arntz, Arntz, and Anton Schmidt. 1989. Perceived control and the experience of pain. In *Stress, Personal Control and Health*. Edited by Andrew Steptoe and Ad Appels. Hoboken: John Wiley and Sons, pp. 131–62.
- Bons-Storm, Maria. 2016. Where is God when dementia sneaks into our house? Practical theology and the partners of dementia patients. *Theological Studies* 72: 1–8. [CrossRef]
- Brown, Kirk Warren, Constance L. Coogle, and Jacob Wegelin. 2015. A pilot randomized controlled trial of mindfulness-based stress reduction for caregivers of family members with dementia. *Aging and Mental Health* 20: 1157–66. [CrossRef] [PubMed]
- Bull, Margaret J. 2013. Strategies for sustaining the self used by family caregivers for older adults with dementia. *Journal of Holistic Nursing* 32: 127–35. [CrossRef] [PubMed]
- Creswell, John W., and J. David Creswell. 2018. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*, 5th ed. Thousand Oaks: Sage.
- Damianakis, Thecla, Kimberly Wilson, and Elsa Marziali. 2018. Family caregiver support groups: Spiritual reflections' impact on stress management. *Aging and Mental Health* 22: 70–76. [CrossRef] [PubMed]
- Family Caregiver Alliance [FCA]. 2016. *Caregiver Statistics: Health, Technology, and Caregiving Resources*. Available online: <https://www.caregiver.org/resource/caregiver-statistics-health-technology-and-caregiving-resources/> (accessed on 1 June 2022).
- Fauziana, Restria, Rajeswari Sambasivam, Janhavi Ajit Vaingankar, Edimansyah Abdin, Hui Lin Ong, Min-En Tan, Siow Ann Chong, and Mythily Subramaniam. 2018. Positive caregiving characteristics as a mediator of caregiving burden and satisfaction with life in caregivers of older adults. *Journal of Geriatric Psychiatry and Neurology* 31: 329–35. [CrossRef]

- Fife, Benjamin, Lauren Brooks-Cleator, and Jordan P. Lewis. 2020. "The world was shifting under our feet, so I turned to my devotionals as his dementia worsened": The role of spirituality as a coping mechanism for family caregivers of Alaska Native elders with dementia. *Journal of Religion, Spirituality, and Aging* 33: 252–70. [CrossRef]
- Giannouli, Vaitsa, and Konstantinos Giannoulis. 2020. Gazing at Medusa: Alzheimer's dementia through the lenses of spirituality and religion. *Health Psychology Research* 8: 8833. [CrossRef]
- Heo, Grace Jeongim, and Gary Koeske. 2013. The role of religious coping and race in Alzheimer's disease caregiving. *Journal of Applied Gerontology* 32: 582–604. [CrossRef]
- Hughes, Travonia B., Betty S. Black, Marilyn Albert, Laura N. Gitlin, Deidre M. Johnson, Constantine G. Lyketsos, and Quincy M. Samus. 2014. Correlates of objective and subjective measures of caregiver burden among dementia caregivers: Influence of unmet patient and caregiver dementia-related care needs. *International Psychogeriatrics* 26: 1875–83. [CrossRef] [PubMed]
- Kaye, Judy, and Karen Robinson. 1994. Spirituality among caregivers. *The Journal of Nursing Scholarship* 26: 218–21. [CrossRef] [PubMed]
- Kazmer, Michelle M., Robert L. Glueckauf, Gabriel Schettini, Jinxuan Ma, and Michelle Silva. 2018. Qualitative analysis of faith community nurse-led cognitive-behavioral and spiritual counseling for dementia caregivers. *Qualitative Health Research* 28: 633–47. [CrossRef] [PubMed]
- Kevern, Peter, and Hans Stifoss-Hanssen. 2020. The challenges of dementia care and the (un)making of meaning: Analysis of an online forum on carer spirituality. *Dementia* 19: 1220–36. [CrossRef]
- Kezirian, Olivia. 2019. Rural, urban, and suburban differences of formal and informal support systems on the prevalence of caregiver burden in dementia and Alzheimer's-related caregivers. *Alzheimer's and Dementia* 15: P1567. [CrossRef]
- Li, Ryan, Claudia Cooper, Jonathan Bradley, Amanda Shulman, and Gill Livingston. 2012. Coping strategies and psychological morbidity in family careers of people with dementia: A systematic review and meta-analysis. *Journal of Affective Disorders* 139: 1–11. [CrossRef]
- Lloyd, Adriana. 2013. *An Investigation of Spiritual Appraisal in Caregivers for Spouses with Dementia*. Alhambra: Alliant International University, California School of Professional Psychology.
- Mahdavi, Behrouz, Masoud Fallahi-Khoshknab, Farahnaz Mohammadi, Mohommad Ali Hosseini, and Marjan Haghi. 2017. Effects of spiritual group therapy on caregiver strain in home caregivers of the elderly with Alzheimer's disease. *Archives of Psychiatric Nursing* 31: 269–73. [CrossRef]
- McGee, Jocelyn Shealy, and Dennis Myers. 2014. Sacred relationships, strengthened by community, can help people with mild or early-stage Alzheimer's disease. *Generations* 38: 61–67.
- McGee, Jocelyn Shealy, Dennis R. Myers, Holly Carlson, Anegele P. Funai, and Paul A. Barclay. 2013. Spirituality, faith and mild Alzheimer's disease. *Research in the Social Scientific Study of Religion* 24: 221–57.
- McGee, Jocelyn Shealy, Morgan Davie, and Dennis Myers. 2021a. Family caregivers of persons with mild dementia share their spiritual struggles. *Innovation in Aging* 5: 505–6. [CrossRef]
- McGee, Jocelyn, Dennis R. Myers, Rebecca Meraz, and Morgan Davie. 2021b. Caring for a family member with early stage Alzheimer's disease: Caregiver perceptions, connections, and relational dynamics with the sacred. *Journal of Religion, Spirituality and Aging* 34: 196–207. [CrossRef]
- McGee, Jocelyn Shealy, Morgan Davie, Rebecca Meraz, Dennis Myers, and Micheala McElroy. 2022. 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. *Religions* 13: 645. [CrossRef]
- Merriam, S. B. A. 2002. *Qualitative Research in Practice: Examples for Discussion and Analysis*, 1st ed. San Francisco: Jossey-Bass.
- National Alliance for Caregiving. 2020. Caregiving in the U.S. Available online: <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf> (accessed on 1 June 2022).
- National Institute on Aging. 2022. End of Life Care for People with Dementia. Available online: <https://www.nia.nih.gov/health/end-life-care-people-dementia> (accessed on 1 June 2022).
- Netto, Nicholas Rapheael, Goh Yen Ni Jenny, and Yap Lin Kiat Philip. 2009. Growing and gaining through caring for a loved one with dementia. *Dementia* 8: 245–61. [CrossRef]
- Nowell, Lorelli S., Jill M. Norris, Deborah E. White, and Nancy J. Moules. 2017. Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods* 16: 1609406917733847. [CrossRef]
- Nowlan, Jamie S., Viviana M. Wuthrich, and Ronald M. Rapee. 2015. Positive reappraisal in older adults: A systematic literature review. *Aging and Mental Health* 19: 475–84. [CrossRef] [PubMed]
- Pargament, Kenneth I. 1997. *The Psychology of Religion and Coping: Theory, Research, Practice*. New York: Guilford Press.
- Pargament, Kenneth I. 2002. The bitter and the sweet: An evaluation of the costs and benefits of religiousness. *Psychological Inquiry* 133: 168–81. [CrossRef]
- Pargament, Kenneth I. 2007. *Spiritually Integrated Psychotherapy: Understanding and Addressing the Sacred*. New York: Guilford Press.
- Pargament, Kenneth I. 2011. Religion and coping: The current state of knowledge. In *Oxford Handbook of Stress, Health, and Coping*. Edited by Sisan Folkman. Oxford: Oxford University Press.
- Pargament, Kenneth I., Harold G. Koenig, and Lisa M. Perez. 2000. The many methods of religious coping: Development and initial validation of RCOPE. *Journal of Clinical Psychology* 564: 519–43. [CrossRef]

- Pargament, Kenneth I., Melissa D. Falb, Gene G. Ano, and Amy B. Wachholtz. 2013. The religious dimension of coping: Advances in theory, research, and practice. In *The Handbook of the Psychology of Religion*. Edited by Raymond F. Paloutzian and Crystal L. Park. New York: Guilford Press, pp. 560–80.
- Pietkiewicz, Igor, and Jonathon A. Smith. 2014. A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. *Czasopismo Psychologiczne Psychological Journal* 20: 7–14. [CrossRef]
- QSR International Pty Ltd. 2022. NVivo (Release 1.6.1). Available online: <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home> (accessed on 26 June 2022).
- Riffin, Catherine, Peter H. Van Ness, Jennifer L. Wolff, and Terri Fried. 2017. Family and other unpaid caregivers and older adults with and without dementia and disability. *Journal of the American Geriatrics Society* 65: 1821–28. [CrossRef]
- Rothbaum, Fred, J. R. Weisz, and Samuel S. Snyder. 1982. Changing the world and changing the self: A two-process model of perceived control. *Journal of Personality and Social Psychology* 42: 5–37. [CrossRef]
- Saffari, Mohsen, and Hui Chen. 2019. Mediating effect of spiritual coping strategies on caregiving burden and mental health in caregivers of Iranian patients with dementia. *Social Health and Behavior* 2: 117–26. [CrossRef]
- Salamizadeh, Azam, Tayebeh Mirzaei, and Ali Ravari. 2017. The impact of spiritual care education on the self-efficacy of the family caregivers of elderly people with Alzheimer's disease. *International Journal of Community Based Nursing and Midwifery* 5: 231–38.
- Shim, Bomin. 2020. Reflections on the spiritual lives of caregivers of spouses with dementia: Receiving grace. *Journal of Christian Nursing* 37: E13–E16. [CrossRef]
- Shin, Sadie, Matthew Huddleson, Lisa M. Brown, Teceta Tormala, and Rowena G. Gomez. 2017. The role of religion in caregiver burden and depression for family caregivers of dementia patients. *Innovation in Aging* 1: 139. [CrossRef]
- Smith, Jonathon A., Paul Flowers, and Micheal Larkin. 2009. *Interpretative Phenomenological Analysis: Theory, Method and Research*. Thousands Oaks: SAGE.
- Stuckey, Jon C. 2001. Blessed assurance: The role of religion and spirituality in Alzheimer's disease caregiving and other significant life events. *Journal of Aging Studies* 15: 69–84. [CrossRef]
- The Carter Center. 2011. Written Testimony of Former First Lady Rosalynn Carter Before the Senate Special Committee on Aging. Available online: https://www.cartercenter.org/news/editorials_speeches/rosalynn-carter-committee-on-aging-testimony.html (accessed on 1 June 2022).
- Tomás, Caria, and Pedro J. Rosa. 2021. Validation of a Scale of Religious and Spiritual Coping (RCOPE) for the Portuguese Population. *Journal of Religion and Health* 60: 3510–29. [CrossRef]
- Waelde, Lynn C., Hillary Meyer, Jason M. Thompson, and Dolores Gallagher-Thompson. 2017. Randomized controlled trial of inner resources meditation for family dementia caregivers. *Journal of Clinical Psychology* 73: 1629–41. [CrossRef]
- Xu, Jianbin. 2016. Pargament's theory of religious coping: Implications for spiritually sensitive social work practice. *British Journal of Social Work* 46: 1394–410. [CrossRef]