



Elise K. Eifert

Religious Coping While Providing Care for Someone with Alzheimer's Disease

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Caring for a family member with Alzheimer's disease and related dementia has been recognized as a source of stress that can negatively impact the health and well-being of the caregiver. Coping strategies for the family caregiver may help him or her diminish this impact. Growing attention has been focused on the relationships between religious coping, stress, and health outcomes among family caregivers. For this article, the literature was examined in an attempt to understand religion as a source of support and means of coping among individuals providing care to a family member with Alzheimer's disease and related dementia.

I have been surrounded by Alzheimer's disease (AD) most of my life. My great-grandfather was diagnosed with AD when I was in grade school, followed by my maternal grandmother who also had AD, and then by my paternal grandmother who had vascular dementia. Not to mention all the residents—most had some form of dementia—who lived in the nursing home that my father was the administrator of and where I visited frequently throughout my adolescence (mostly to play bingo). I am not sure any disease related to aging causes more fear than Alzheimer's disease and related disorders (ADRD). The slow descent into darkness that accompanies many progressive forms of dementia, such as AD, is devastating. For the person with ADRD, we can only hope that they are unaware, but what about the family members left behind?

For every person with ADRD, there is a caregiver, most likely a family member such as a spouse or adult child. In my family's case, there were multiple family caregivers stoically providing direct and indirect assistance. As a young person, I was mostly oblivious to the hardships that probably accompanied this role. As an adult, I recognize the toll this had to

have taken on individual family members. Watching a person you know and love disappear little by little until he or she is a shell of their former self had to be heartbreaking. I believe that these childhood experiences with ADRD shaped my career choices. My first job after college was as an ADRD educator for a local, not-for-profit in Florida. Later, I earned a PhD in public health education with a post-baccalaureate certificate in gerontology. I have been studying family caregiving ever since.

In my career, I hear a lot of personal caregiving stories. Although each experience is unique, there are similar threads. One such thread is the stressful, life-consuming nature of caregiving that often impacts the health of the person providing the care. Caregivers experience numerous stressful events that occur concurrently and continue over time. The impact of this stress is known as "caregiver burden." There is no single agreed-upon definition of caregiver burden;¹ however, caregiver burden can be

Elise Eifert earned a PhD in public health education from the University of North Carolina (UNCG) at Greensboro, as well as a post-baccalaureate certificate in gerontology. She is currently the program coordinator for the online Master's degree in gerontology at UNCG.

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thought of as a negative reaction to unchecked stress related to caregiving. Studies of family caregivers suggest that stress and burden has a relationship with negative health outcomes such as depression² and overall poor health, including a lowered immune system and higher blood pressure.³ Even more alarming, family caregivers experience a higher mortality rate compared to noncaregivers, presumably due to caregiver burden.⁴

I believe that my great-grandmother faced an enormous amount of this stress and burden while she was caring for her husband. I was far too young to fully understand, but I do know that my great-grandfather was difficult. He was a former judge and professional boxer with a larger-than-life presence, especially next to my petite great-grandmother. Despite her best efforts to keep him at home, he was placed in a skilled nursing facility for his and her safety. She never spoke another word, and she lived for at least three years after that! I am confident that it was because of the guilt, a stress-induced emotion, she felt for placing him in a nursing home.

Unlike her father, my grandmother was quite calm when she developed ADRD. Her husband, my grandfather, cared for her in the most patient and gentle way for as long as possible. She had a tendency to wander, a common occurrence with ADRD, and that put her in danger which ultimately led to placement in a skilled nursing facility. My grandfather visited her daily in the nursing home, often for the entire day. Until her death, he was the most loving, considerate, and grace-filled caregiver.

When I began my research with family caregivers, my family's experience with ADRD and caregiving was front and center. I was particularly interested in the coping styles of the primary caregivers—my great-grandmother and my grandfather. I never had the opportunity to speak with my great-grandmother about her experience and how she dealt with the stress of caregiving. Conversely, I spoke with my grandfather at great lengths. When I asked him how he handled the stress of his wife's disease and providing care to her, he consistently responded—God's grace! My grandfather was a devoutly religious man who attended church services regularly. He sang in the choir and was a member of men's groups who served the community. His pastor and brothers and sisters in Christ provided spiritual support as well as emotional support throughout my grandmother's ill-

ness. God was the foundational rock he stood upon to deal with caregiving.

My grandfather's reliance on his religion and religious community is not uncommon among caregivers. Religion, as well as spirituality, serves as a coping mechanism for stressful times and life events. The power of this is particularly demonstrated during caregiving for a frail or sick family member, especially one with ADRD. According to a recent report on caregiving, religion/spirituality is one of the most important coping mechanisms for caregivers.⁵ Kaye and Meier Robinson found a positive correlation between the criticalness of a care situation and the caregiver's reliance on religion.⁶ In this article, I examine religion as a source of support and means of coping among individuals providing care to a family member with ADRD.

Family Caregiving

According to the most recent Alzheimer's Disease Facts and Figures report, 15 million Americans provide unpaid care to an adult with ADRD.⁷ This number is expected to increase in the next couple of decades due to a variety of factors, the most obvious being the growing baby boomer population of people 65 and older. Caregiving for someone with ADRD encompasses a wide range of activities from occasionally running errands to supervising regular activities to direct day-to-day care. Traditionally, responsibilities include assistance with activities of daily living, such as bathing, dressing, and eating, as well as instrumental activities of daily living, such as money management and transportation.⁸ Caring for a person with ADRD is often complicated by symptoms of the condition, including a lack of judgment, communication difficulties, and behavioral symptoms such as aggression or wandering.

Of growing concern is the increasing complexity of providing care. Many caregivers report performing medical/nursing tasks of the kind and complexity once provided only in hospitals such as medication management, including administering IVs and injections, wound care, operating specialized medical equipment, and physical or medical therapies or treatments.⁹ Much of the advanced care provided is done with little to no training.¹⁰ The amount of time spent on caregiving can be a few hours a week to 24 hours/7 days a week, depending on the needs of the person with ADRD and/or the presence of other

caregivers. On average, a family caregiver of someone with ADRD spends 21.9 hours per week carrying out care-related responsibilities.¹¹ Moreover, caregivers of people with ADRD provide care for a longer time than do caregivers of older adults with other conditions; the majority provided care for six or more years.¹²

The large quantity of care needs and the amount of time required to carry out this care can be a major influence on the caregiver's life and health. Although there are many positive aspects of caregiving such as companionship, fulfillment, enjoyment, and the satisfaction of meeting an obligation and providing quality of life to a loved one,¹³ caregiving often takes a toll. Studies have linked family caregiving to a variety of long-term health problems.¹⁴ For this reason, learning to cope as a caregiver is essential for survival. An array of coping strategies used by family caregivers, including religious coping, emotional coping, acceptance, becoming engaged in leisure activities, and the use of traditional healing, can be utilized.¹⁵ However, religious coping may be particularly relevant and adaptive for dealing with the stress and burden of caregiving.

Religious Coping

Religion is a prominent force in many people's lives. Recent data estimate that 89% of American adults believe in God.¹⁶ In a Pew research poll, 75% of people indicate that religion is very important in their lives, 49% attend religious services at least once a week, 74% pray daily, and 50% read scripture at least once a week.¹⁷ Most importantly, 71% had feelings of peace and well-being because of their belief in God.¹⁸ In caring for a family member with ADRD, caregivers continually assess their resources and coping abilities. Thus, it is not surprising that individuals would utilize their religious beliefs, practices, and relationships during this time.

Pearce described religious coping as the "particularly sacred means one uses to find significance in difficult situations"¹⁹ whereas Pargament defined it more broadly as "the use of religious beliefs or behaviors to facilitate problem-solving to prevent or alleviate the negative emotional consequences of stressful life circumstances."²⁰ These definitions both imply that coping is a conscious attempt to address stress or manage stress in times of crisis. Whereas Pearce suggests that religious coping is finding

meaning in that stress, the more frequently used definition by Pargament suggests that religious coping is related to stress management. Pearce's definition is one-dimensional and falls under the auspices of Pargament's definition.

Religious coping can be separated into two patterns: (1) positive religious coping or turning to religion during stressful times (e.g., forgiveness, collaborative problem-solving with God, religious purification, benevolent religious reappraisals, spiritual connection with others) and (2) negative religious coping or turning away from religion during stressful times (e.g., punitive religious appraisals, demonic reappraisals, spiritual discontent, self-directing coping efforts). Positive religious coping is more common.²¹ Coping, in general, refers to adaptive or constructive strategies. In addition, negative strategies are typically unproductive. For these reasons, positive religious coping is more extensively addressed in the literature and promoted in practice. Positive religious coping is emphasized in this article. Any reference to religious coping from this point forward will relate to positive religious coping unless otherwise stated.

Religious coping is multidimensional. Pargament, Koenig, and Perez identified six dimensions of religious coping:

1. *Spiritually based*—the degree to which one copes through a personal relationship or connection with God and one's faith;
2. *Good deeds*—the degree to which one copes by committing oneself to living a more religious life;
3. *Religious avoidance*—the degree to which one copes by using religious behavior or God to divert attention away from the stressor;
4. *Discontent*—the degree to which one copes by expressing anger at God or one's religious community;
5. *Interpersonal religious support*—the degree to which one copes by receiving assistance from one's religious community; and
6. *Pleading*—the degree to which one copes by questioning or bargaining with God, including requests for miracles.²²

In Harrison and colleagues' examination of the epidemiology of religious coping, they identified several studies that indicate the prevalence of religious coping, or at least religious activities that could be construed as religious coping, within populations

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facing stressful health crises.²³ Koenig found that 73% of medically ill, hospitalized patients use religion as a coping strategy,²⁴ whereas Ayele and colleagues found 86% of hospitalized and long-term care patients used religious activities to cope.²⁵ In a study of cancer patients, 75% said that they spend time in private religious activities.²⁶

Several studies suggest that a crisis increases religious activities; for example, Kirov and colleagues found that 30% of psychotic inpatients reported an increase in religiousness from the onset of their disorder,²⁷ and Roberts and associates found that 50% of gynecological cancer patients reported becoming more religious since being diagnosed.²⁸

Among family caregivers, several studies have indicated the use of religious coping strategies. Rammohan found that 97% of caregivers for relatives with schizophrenia believed in God while 50% considered religion a source of strength and guidance.²⁹ Stolley and associates found that 61% of caregivers for relatives with AD “trusted in God” as a way to cope.³⁰ Another study with AD caregivers found that 96% considered themselves religious and reported high levels of religious coping.³¹ Cohen and colleagues found that 21% of caregivers for someone with dementia named religion as the most important determinant of quality of life.³²

Forms of Religious Coping

To better understand religion's role in the coping process of family caregivers, it is important to examine the multiple ways in which people utilize their religion. Pargament and colleagues identified distinct broad approaches in which caregivers look to God for help—all centered on seeking control of the caregiving situation.³³ Their premise was that optimal coping is the coordination of primary (i.e., internal resources) and secondary (i.e., external resources) control processes that increase the caregiver's ability to handle stress-inducing problems related to caregiving. The approaches include the following:

- *Self-directing*. In this approach, caregivers seek the knowledge, abilities, tools, and resources given to them by God to gain control of the situation through the self.
- *Deferring*. In this approach, caregivers surrender to God, acknowledging that ultimate control and responsibility belong to God.

- *Collaborative*. In this approach, caregivers are in a partnership with God. Caregivers seek the knowledge, abilities, tools, and resources given to them by God, but also acknowledge that ultimate control and responsibility belong to God.

An individual can use any of the approaches to manage life stressors, but the *collaborative* approach has been shown to be the most common and effective.³⁴ Wong-McDonald and Gorsuch suggest that religious coping strategies vary according to an individual's degree of religious commitment.³⁵ Logically, less-religious individuals tend to use the *self-directed* approach while more-religious individuals utilize the *deferring* and *collaborative* approaches.

Specific religious coping methods vary—from a general religious orientation or belief in God to actual religious practices and behaviors. Generally speaking, just believing in God has been shown to affect a caregiver's appraisal of the caregiving situation³⁶ and give the caregiver purpose.³⁷ Specifically, in order to cope caregivers may attend religious services; pray; read religious material; meditate; participate in prayer groups, study groups, or religious education programs; or seek support from members and clergy of their religious institution. An instrument that may be helpful in understanding specific forms of religious coping is the Ways of Religious Coping Scale (WORCS).³⁸ WORCS was developed to assess internal and external religious coping cognitions and behaviors. Internal forms of religious coping were considered to be activities done privately, such as prayer, while external forms of religious coping were more social, such as asking clergy for counsel. WORCS provides a comprehensive list of religious activities that caregivers may participate in to cope with caregiver burden and may be helpful in understanding exactly what falls under the umbrella of religious coping.

To understand the function of religious coping rather than specific behaviors related to religious coping is critical. For example, it is not enough to know that a caregiver prays or attends religious services. The content of the prayers and the types of support sought from religious services is more meaningful in understanding the significance of religious coping.³⁹ Pargament, Koenig, and Perez developed the Religious Coping Activities Scale (RCOPE) to measure religious coping methods in depth.⁴⁰ RCOPE was based on five general functions of religion:

(1) finding meaning, (2) gaining control, (3) gaining comfort and closeness to God, (4) gaining intimacy with others, and (5) achieving a life transformation. Under each function, multiple items and subscales were created to assess how the person sought that specific function and the meaning he or she ascribed to it. The authors intentionally made the instrument comprehensive to capture active, passive, and interactive coping methods as well as problem-focused and emotion-focused approaches. Additionally, the RCOPE covers cognitive, behavioral, interpersonal, and spiritual domains of religious coping. RCOPE provides a more nuanced picture of religious coping and may be useful to researchers and practitioners interested in a comprehensive assessment of religious coping.

Benefits of Religious Coping

As with other coping strategies, religious coping has been found to mediate and moderate the relationship between stress and health. Interest in this relationship, especially among family caregivers, has increased dramatically in the past several decades. For this reason, there is a great deal of literature concerning religious coping. Researchers continue to explore which aspects of religious coping influence health and the mechanisms for the observed relationships.

Stress generally refers to two things: (1) the psychological perception of stressors, and (2) the body's biological response to the stressors, which involves multiple systems from metabolism to muscles to memory.⁴¹ Over time, repeated activation of the stress response takes a toll on the body. Research suggests that chronic stress contributes to high blood pressure, promotes the formation of artery-clogging deposits, and causes brain changes that may contribute to anxiety, depression, and addiction.⁴² For the aged, stress has the potential to be especially overwhelming.⁴³ Older adults have a tendency to be less resilient to stress. Heart fitness and lung capacity decline with age; these conditions keep elders from adequately accommodating the body's natural stress response. This may be exacerbated by the presence of a chronic disease, which is already a burden on the body.

Broadly speaking, religious coping has two distinct roles in the stress-health relationship. In the first role, the presence of religious coping helps buffer, or

shield, a caregiver from the negative impact of stress. In other words, as stress levels increase, caregivers who use religious coping are better protected from the harmful effects of stress than are their less-religious counterparts. In the second role, stress exerts its negative effects on health, but religious coping works in the opposite direction, acting as a deterrent to stress. These roles are not exclusive to each other but actually work in tandem, so Pargament suggested the *Religious Moderator-Deterrent* model.⁴⁴ According to the model, religious coping

serves a moderating function in that as stress levels rise, religious coping increasingly protects religious people from the harm of stress; concurrently, religious coping performs a deterring function because it is a reliable predictor of more favorable outcomes no matter how intense stress is.⁴⁵

Because of this dual function, religious coping is considered to be both a mediator and a moderator for the relationship between stress and health.

Several comprehensive literature reviews have been conducted to identify studies that elucidate the concept of religious coping.⁴⁶ A few have specifically focused on religious coping among family caregivers.⁴⁷ These literature reviews outline the science linking religious coping, stress, and health of family caregivers (not necessarily specific to ADRD) in the past 30 years. For brevity, positive religious coping has been found to have a significant relationship with mental health (e.g., depression, psychological distress, grief, self-esteem),⁴⁸ social functioning and support,⁴⁹ quality of life and life satisfaction,⁵⁰ health-promoting behaviors (e.g., diet, physical activity, sleep, healthcare engagement),⁵¹ happiness,⁵² and adjustment and satisfaction with caregiving among family caregivers.⁵³

Despite the ample amount of scientific data linking religious coping to stress and health, there are still significant gaps and limitations in our understanding of the exact role of religious coping. The aforementioned studies all found a favorable link between religious coping and stress or health of family caregivers; however, some studies have yielded nonsignificant or mixed findings.⁵⁴ This can mostly be attributed to studies not using valid and reliable measures of religious coping and participants using other forms of coping in addition to religious coping. Some studies generally asked about religious coping and counted anything remotely spiritual as religious

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coping. Other studies did not control for non-religious forms of coping and their influence in the stress-health relationship. Furthermore, little information is provided regarding "how religious coping works for caregivers, for whom and what outcomes it is most effective, when it may be harmful, or how it changes over time."⁵⁵ The difficult questions, "What type of religion, what effect, what circumstances, via what mechanisms, and for whom?" are still being determined.⁵⁶

Limitations to Religious Coping

As mentioned previously, caregivers have a range of coping strategies to choose from but not all caregivers will choose religious coping. Religious coping is dependent on personal factors (e.g., demographic, personality, or religious), characteristics of the challenge (e.g., types or numbers of stressors, or time since a stressful event), or characteristics of the wider context of the stressful event.⁵⁷ Among some groups, particularly the elderly and minorities, religious coping is cited more frequently than any other form of coping.⁵⁸ Additionally, differences in likelihood of use and significance of religious coping can be found among those with lower education, higher levels of social support, or more stressful life events.⁵⁹ It is important to recognize these differences when assessing and making decisions regarding religious coping. Furthermore, much of the research on religious coping has been conducted with western, Christian populations. Findings from scientific literature and information presented here may not be applicable across all Christian denominations or with non-Christian religions. Religions come in many "shapes and sizes" and these differences have tremendous impact on values, morals, behavior, and culture that make the universality of religious coping unknown.

This article focused on positive religious coping, but it is also important to acknowledge negative religious coping by family caregivers. Much less research on negative religious coping has been conducted with family caregivers.⁶⁰ That is not to say it does not occur. For some family caregivers, feelings of anger and resentment and wondering if God has forsaken them are understandable. It is difficult not to ask why God allows ADRD to happen. For caregivers, the real issue may not be why something like ADRD happened, but how to respond to it in a godly way. Religious communities need to be prepared

for this negative reaction to ADRD and caregiving. Another roadblock for many religion-centric caregivers is the time and energy required for religious practices. Many caregivers are consumed by caregiving, leaving little time to attend a religious service or read religious material. Even if the caregiver did find the time to participate in their religious community, the care recipient perhaps cannot be left alone or be expected to sit through a long religious service. This may lead to the caregiver becoming isolated and without their main avenue to connect with their religion, possibly reinforcing or supporting negative coping. Finally, religious coping is not always associated with an active approach to dealing with stress or health issues. An argument could be made that some people delay asking for help or support because they are waiting on miraculous divine intervention that may never happen. Much more research on the prevalence and impact of negative religious coping on family caregivers, and how clergy and churches can respond to negative religious coping, is needed.

Implications for Supporting Caregivers

For anyone who knows, loves, or works with family caregivers, it is important to acknowledge the role religion may have in their lives.

Clinicians

According to Harrison and colleagues, clinicians should ask caregivers if and how they use religion to help them cope.⁶¹ If the caregiver is currently using forms of religious coping in a healthy manner, the clinician should support and encourage the behaviors. However, if the caregiver is not currently utilizing religious coping, it is best that the clinician avoid "prescribing" forms of religious coping. Additionally, it may be helpful for clinicians to work with an individual's clergy to address caregiving issues.

Clergy and Other Religious Leaders

For clergy who play a significant part in many caregivers' religious coping, it is important to give increased attention to their spiritual needs and active participation in the religious community of family caregivers. Veroff, Kulka, and Douvan found that when personal crises occur, people are more likely to seek assistance from clergy than from a mental health professional.⁶² Clergy can provide support and assistance to the members of their congregation in a number of different ways including counseling or

introducing initiatives such as meal delivery, respite, or home maintenance provided by other members of the religious community. In particular, clergy need to welcome and encourage caregivers and care recipients to attend religious services even if the care recipient may be disruptive. This includes reminding other members of the religious community to be understanding and supportive. Just as most religious communities have learned to accept a crying baby during services, religious communities must learn to accept their elders who are struggling with AD RD.

Congregation Members and Church Ministries

For congregation members looking to be of assistance to family caregivers, consider initiating or leading initiatives in your own religious community. Something as simple as a friendly visit or weekly phone call to a caregiver can prevent the caregiver from feeling isolated and alone. It can also alleviate frustration from a caregiver who feels forgotten by the religious community to which he or she gave years of service.⁶³

As the population of older adults increases due to increased longevity and the aging of baby boomers, religious communities will need to learn how to address the unique needs of their aging members. Large religious communities or, at least, religious communities with large aging populations may want to consider a ministry dedicated to elders or family caregivers. Caregivers may be able to provide better care for a longer time when their religious communities surround and support them. From a biblical perspective, religious communities are called to show love and mercy (John 15:13), provide hospitality (Mark 6:37–44), and help those in need of assistance (Job 29:12), especially the marginalized (Matthew 25:40). From a societal perspective, very few social institutions are as well placed to “care for the caregiver” as is the church. Public and government assistance is not available or not enough for family caregivers. The church may be the only source of support available. Considering that family caregivers provide \$470 billion worth of care services and are the largest source of long-term care in the United States, we should support them.⁶⁴

Conclusion

Caregiving for a family member with AD RD can be a stressful experience that takes a toll on the health

and well-being of the caregiver. In an effort to ameliorate this stress, caregivers rely on a variety of coping strategies including religious beliefs and practices. This article attempts to summarize the scholarship behind religion as a source of support and means of coping among individuals providing care to a family member with AD RD.

Religion can provide family caregivers with a sense of control through human initiative and divine power. Paul states in Romans 8:35–37, NABRE:

What will separate us from the love of Christ? Will anguish, or distress, or persecution, or famine, or nakedness, or peril, or the sword? As it is written:

“For your sake we are being slain all the day;
we are looked upon as sheep to be slaughtered.”

No, in all these things we conquer overwhelmingly through him who loved us.

Although AD RD is a frightening disease and caregiving is a struggle, nothing can separate us from the love and grace of God. My grandfather believed it, and scientific evidence supports his claim. Through religious coping, caregivers of individuals with AD RD can be strengthened spiritually, physically, and mentally. In all the uncertainties that caregiving brings, God’s love is steady—“It bears all things, believes all things, hopes all things, endures all things” (1 Cor. 13:7). If caregivers can hold on to this, their caregiving experience may be less stressful and burdensome. ❖

Notes

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