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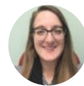

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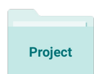

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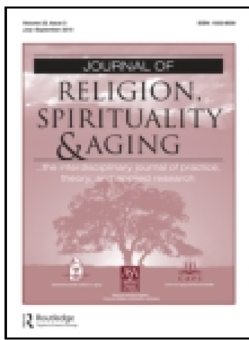

Journal of Religion, Spirituality & Aging

Routledge
Taylor & Francis Group

ISSN: 1552-8030 (Print) 1552-8049 (Online) Journal homepage: http://www.tandfonline.com/loi/wrsa20

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To cite this article: Amy Weisman de Mamani, Marc J. Weintraub, Carolina C. Tauler, Kayla Gurak, Jessica Maura, Michael G. Mejia & Stephen Sapp (2014) Religion and Free Will Perceptions as Coping Mechanisms in Caregivers of Individuals With Dementia: A Review of the Literature, Journal of Religion, Spirituality & Aging, 26:2-3, 201-214, DOI: 10.1080/15528030.2013.829017

To link to this article: http://dx.doi.org/10.1080/15528030.2013.829017

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Journal of Religion, Spirituality & Aging, 26:201–214, 2014
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ISSN: 1552-8030 print/1552-8049 online
DOI: 10.1080/15528030.2013.829017

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Religion and Free Will Perceptions as Coping Mechanisms in Caregivers of Individuals With Dementia: A Review of the Literature

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Looking after a person with a mental illness takes a profound toll on the caregiver (Spurlock, 2005; Suro & Weisman de Mamani, 2013). Pinpointing beliefs and practices that can ameliorate this distress is critical. Inferring from related literatures, we propose that individuals who are more religious and endorse greater perceptions of free will may adapt more effectively to the stresses associated with caregiving. Implications from this review suggest that promoting adaptive religious beliefs and fostering the notion of free will may serve as beneficial strategies for caregivers of individuals with dementia. More empirical research on this topic is clearly warranted.

KEYWORDS *dementia, caregivers, religion, free will perceptions, caregiver burden*

Karel, Gatz, and Smyer (2012) describe the United States as "an aging country in an aging world." They warn that the decade ahead will present significant health care, policy, and financial challenges related to an aging population that cannot be ignored by psychologists. One such challenge will be responding to the increasing prevalence of dementia and related diseases. Dementia is an umbrella term used to describe a variety of conditions that develop when nerve cells in the brain no longer function properly or die off (Thies & Bleiler, 2012). The worldwide prevalence of dementia is around

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35.6 million; this number is estimated to increase fourfold, to 115 million, by 2050 (Van den Dungen et al., 2012).

The most common form of dementia is Alzheimer's disease (AD). According to the 2012 Alzheimer's Association report, approximately 5.4 million people in the United States have Alzheimer's disease (AD), making it the fifth leading cause of death in Americans over age 65 (Thies & Bleiler, 2012). Though several existing drugs appear to improve symptoms temporarily, there is currently no FDA-approved treatment to stop or appreciably slow progression of the illness. Therefore, helping individuals with dementia and their loved ones cope with the illness and its deteriorating course is vital. AD and other age-related dementias are usually chronic. The duration of illness estimates range from three to four years in community settings (Graham et al., 1997) to ten to twelve years in clinical settings (Rabins, Lyketsos, & Steele, 2006). This poses a unique public health problem with serious effects on persons with dementia, their families, and society at large.

In the United States alone, it is estimated that by 2050 the annual cost of dementia will be close to $400 billion in direct and indirect expenses (Murman 2001; Murman, Von Eye, Sherwood, Liang, & Colenda, 2007). This number is estimated to rise exponentially in the coming years as the baby boomer generation continues to age (Thies & Bleiler, 2012). Although dementia can occur at any age, it is most commonly seen in older individuals, and the prevalence increases dramatically with age (Lyketsos, 2012). The majority of care for individuals with dementia (even those with severe dementia) is provided by families, so most individuals with dementia are living at home, not in a nursing facility, when they die (Callahan et al., 2012). In 2011, more than 15 million family members provided an estimated 17.4 billion hours of unpaid care to people with AD, and the majority of these caregivers (56%) are elderly themselves (Thies & Bleiler, 2012). This provides additional challenges because most people with AD need assistance with activities of daily living (e.g., bathing), which can be especially taxing for the elderly caregivers who themselves may suffer from age-related physical decline.

Not surprisingly, caring for a loved one with dementia is often accompanied by high levels of depression, anxiety, and stress, along with a host of other burdens such as financial strain (Shah, Snow, & Kunic, 2001; Spurlock, 2005; Thies & Bleiler, 2012). The Alzheimer's Association 2012 report indicated that 61% of dementia caregivers rate their emotional stress as very high, 33% report serious symptoms of depression, and 75% report substantial concerns in maintaining their own health since becoming a caregiver (Thies & Bleiler, 2012). Research that focuses on how to mitigate the stresses and aid the growing segment of society caring for a loved one with dementia is therefore critical.

While more research is needed, there is some evidence to suggest that religious beliefs and practices and a perception that one maintains free will

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may help caregivers adapt to their caregiving role more effectively. The aim of the current article is to review this literature. We begin by defining our primary terms (dementia, caregivers, religion, and free will). Next we review prior research on religion and free will as they pertain to caregiver's reactions to dementia. We end the article with a case vignette that illustrates how the difficulties of caregiving for a person with dementia can be mitigated by a strong sense of free will and a connection to God.

DEFINITIONAL CLARIFICATIONS

Caregiver

In this article we use the term "caregiver" to refer to an informal, unpaid person (generally a family member) who provides the majority of care for a person with dementia.

Dementia

We define "dementia" using the following criteria outlined in the fourth, text-revised, edition of the Diagnostic and Statistical Manual (American Psychiatric Association, 2000): prominent memory decline and at least one other area of cognitive decline such as the ability to generate coherent speech, recognize objects, or make sound judgment. It is important to note that in the latest revision of the DSM manual (DSM-5), the term dementia was eliminated and replaced with the phrase "major and minor neurocognitive disorder." One of the reasons reported for this change is that the term "dementia" is not well accepted by younger people with HIV and other non-age-related causes (Siberski, 2012). However, the majority of individuals with dementia and their caregivers are elderly; thus we chose to retain the term "dementia" as formerly defined by the DSM-IV-TR.

Religion

Although there is a growing tendency to conceive of the terms "religion" and "spirituality" as distinct constructs, there is no clear consensus about their definitions. Spirituality, often conceptualized as broader than religion (Roof, 1999; Weisman de Mamani, Wasserman, Duarte, Koneru, & Llerena, 2010), refers to a range of nonmaterial and existential matters (e.g., hope, trust). Religion on the other hand is generally associated with the more formal and organized aspects of knowledge, beliefs, and practices associated with a particular faith (Shiraev & Levy, 2013). The latter term better captures the focus of this review. Hence, we will primarily use the term "religion" in the current article.

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Free Will

"Free will" refers to the ability of agents to make choices that are free from constraints. More specifically, Baumeister, Crescioni, and Alquist (2011) define it as a unique form of action control that aids in meeting the increasing demands of human life, especially moral action and the pursuit of enlightened self-interest.

RELIGION AND HEALTH

There is a large and growing body of research indicating that various dimensions of religion, religious involvements, and religious practices provide health benefits that mitigate some of the deleterious effects of stress (e.g., Hill & Pargament, 2008; Leblanc, Driscoll, & Pearlin, 2004; Weisman de Mamani, Tuchman, & Duarte, 2010, for a review). Individuals who are more religious and engage in more religious practices tend to have greater personal adjustment, higher self-esteem, lower levels of drug and alcohol abuse, less sexual permissiveness, and lower rates of suicide (Pargament et al., 1988; Pargament, Koening, Tarakeshwar, & Hahn, 2004; Waite, Hawks, & Gast, 2000). A comprehensive meta-analysis also demonstrated that greater religious involvement was associated with lower odds (odds ratio = 1.29; 95% confidence interval: 1.20–1.39) of dying prematurely (McCullough, Hoyt, Larson, Koenig, & Thoresen, 2000).

The benefits of religion appear to extend to caregivers of individuals coping with dementia. Stolley, Buckwalter, and Koenig (1999) found that greater reported spiritual well-being was strongly associated with lower levels of caregiver burden in family members of persons with AD. Koenig (1999) found that caregivers of persons with Alzheimer's disease often perceived that prayer and trusting in God helped them cope more effectively with their loved one's illness. Shreve-Neger (2004) found that religious service attendance moderated the relation between memory and behavior problems and anxiety in caregivers of persons with dementia. Even in the case of mild cognitive impairment, Blieszner and Roberto (2010) found that depressive symptoms tend to be lower in caretakers who reported greater perceived importance of religion.

Religion may be particularly salient for Alzheimer's caregivers given that the majority of these individuals are elderly themselves. In his book *When Alzheimer's Strikes!*, Sapp (2002) reported that many religious congregations have an even higher percentage of older members than the population in general. Thus turning to religion to ease caregiver burden may be especially sanctioned for elderly caregivers. Empirical research suggests that in late adulthood greater religion and spirituality are positively associated with greater well-being in a range of areas, including positive relations with others, greater involvement in community life tasks, and

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greater involvement in creative and knowledge-building life tasks (Wink & Dillon, 2008). Several other sources (e.g., Ellor, Kimble, McFadden, & Seeber, 2004; Koenig, George, & Siegler, 1988) also support the view that there is likely a connection between religion and adaptive coping in older populations, including dementia caregivers.

It is important to note that not all studies have found positive associations between religion and pro-social behaviors. In an analog study by Weisman and López (1996), participants were asked to read a vignette of a person described to meet DSM-IV (American Psychiatric Association, 1994) criteria for schizophrenia and imagine that this person was their brother. The results found no associations between religiosity and favorable emotional reactions toward the hypothetical sibling. Moreover, in a later study using the same sample, Weisman (2000) found that participants who endorsed being more religious reported more blaming and accusatory attributions toward the hypothetical sibling. This study used a normative college student sample that likely had limited knowledge of the strong genetic and biological underpinnings of mental illness. Weisman surmised that individuals may be more likely to use religion in a maladaptive manner (e.g., blaming a mentally ill person for his or her limited functioning because "God helps those who help themselves"[1]) when the causal circumstances for the event are ambiguous. With respect to age-related dementias, caregivers may also be less likely to tap into adaptive religious beliefs, values, and practices (or even utilize maladaptive ones) in the early stages of illness. Pro-social religious tenets such as *Tzedakah* (the Jewish obligation to give assistance to the needy) may be more likely to come into play as the disorder progresses and it becomes abundantly clear that a loved one's confusion, memory impairment, and unusual behaviors are the result of a degenerative illness.

Causal Mechanisms

Though not entirely consistent, the preponderance of evidence suggests that religion is associated with better mental and physical health and greater pro-social reactions to others in need. Less clear are the specific mechanisms that account for these benefits. There are numerous ways that religion may aid individuals coping with the distress of a mental illness. For example, Tuchman and Weisman de Mamani (in press) found that meaning-making coping significantly mediated the effect of intrinsic religion (use of religion as a framework to understand life) and quality of life in mentally ill patients. In other words, the adaptive elements of intrinsic religion may be explained by the meaning that religion offers. The authors further found that religious patients with mental illness were more likely to seek social support, which may be another mechanism whereby religion improves mental health. In line with this view, Hebert, Dang, and Schulz (2006) found that caregivers of persons with dementia who attended religious services frequently demonstrated

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less depression and, in the case of recently bereaved caregivers, less complicated grief. The authors suggested that social support was likely a causal mechanism because attendance allows caregivers to interact with people of similar values. Another manner in which religion may benefit caregivers is by targeting their perceptions of free will. This topic will be addressed in the following text.

FREE WILL

As far as we are aware, no research has directly examined free will beliefs in caregivers of persons with dementia and, thus, there is a dearth of related empirical research to draw from. In this section, we will discuss the topic of free will more generally and will then summarize our views on how it can be applied to caregivers of individuals with dementia.

Baumeister, Crescioni, and Alquist (2011) contend that belief in the notion of free will is widespread. This idea is not new. For example, the eminent philosopher Arthur Schopenhauer (1883/1909) wrote, "Everyone believes himself *a priori* to be perfectly free, even in his individual actions, and thinks that at every moment he can commence another manner of life" (p. 147; *The World as Will and Idea*). Baumeister, Crescioni, and Alquist (2011) also contend that belief in free will generally has favorable social consequences. Another seminal thinker, Viktor Frankl, wrote about the benefits of free will perceptions. The following quotation poignantly summarizes Frankl's philosophy:

> Forces beyond your control can take away everything you possess except for one thing, your freedom to choose how you will respond to the situation. You cannot control what happens to you in life, but you can *always* control what you will feel and do about what happens to you. (Kushner, in Frankl, 2006, p. X)

In his renowned book *Man's Search for Meaning,* Frankl recounts that concentration camp workers who were able to maintain a sense of dignity and purpose for which to live were likely to survive longer and keep apathy at bay. Many were devout Jews who, through their religion, were able to find a purpose for living and resist their oppressors. Frankl's premise is that people cannot always control their circumstances, but they can control how they view or react to them.

Proponents of free will argue that, in almost any situation, a person can act or react in more than one manner. In his experiences in four concentration camps, Frankl (2006) observed that great variability existed in the manner in which prisoners reacted to the stress of imprisonment. Some became detached, merely helplessly and hopelessly waiting to die. Others

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became "animals," treating fellow prisoners even worse than did the guards. Frankl also notes that there was a small, albeit noteworthy, number of prisoners who managed to act with humor and kindness and in solidarity with other prisoners, despite all of the excruciating mental and physical controls that were placed on them. Frankl observed that the few who were able to remain positive were those who used the tragedy as an opportunity to find meaning in the experience and maintain hope and dignity regardless of the unlikely possibility of a positive outcome.

Free will is frequently viewed as the antagonist of determinism, a position that leaves no room for free human choice. From the deterministic perspective, everything that happens is the unavoidable product of prior causes (Baumeister, 2008). Psychologists tend to be divided as to whether free will exists. Some argue that it must exist because people make choices and can theoretically choose differently under the same circumstances. Others believe that psychology must explain all behavior in terms of causes. Consequently, if a behavior is caused, it is not truly free (Baumeister & Bushman, 2008). Ultimately, the validity of this view is a philosophical issue. However, whether people *believe* they possess free will and the consequences of this belief (or lack of it) fall squarely within the purview of psychology. This article focuses primarily on the potential advantages to dementia caregivers of holding the perspective that they retain the freedom to choose how to respond to events in their lives, particularly those related to caring for a person with dementia.

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The Study of Free Will in Psychology

The topic of free will has been empirically investigated in only a handful of psychological studies (Baer, Kaufman, & Baumeister, 2008), and none that we are aware of is in the area of dementia. The free will construct has received the most attention in the disciplines of philosophy and religion (Stroessner & Green, 1990). This is likely in part because the most debated question regarding free will, whether people have it or not, does not lend itself readily to the empirical methods required in psychological research. Beliefs and perceptions about free will, on the other hand, can be studied empirically.

Although there is a dearth of empirical research on free will beliefs, some findings indicate that greater perceptions of free will may be beneficial to one's mental health and to those coping with stressful circumstances (e.g., dementia caregivers). Rakos, Laurene, Skala, and Slane (2008) found that a strong sense of free will was associated with higher self-esteem in both adults and adolescents. They made sense of these findings by suggesting that as humans evolved, those who believed they possessed free will were better at manipulating their environment in difficult situations. Thus, they became better at decision making, improved their problem-solving skills, and gained

more self-restraint, which in turn improved their psychological and physical health. Other studies have shown that inducing disbelief in free will tends to reduce willingness to help others and increases aggressive behavior (see Baumeister, Masicampo, & Dewall, 2009), and dishonest behavior, such as cheating on a test (Vohs & Schooler, 2008). Free will perceptions clearly appear to have important emotional, behavioral, and societal ramifications and are therefore highly worthy of further scientific research in psychology.

The Intersection of Religion and Free Will

The notion of free will, whereby people are seen as authors of their own actions, is at the heart of most "Western" (or more accurately, Abrahamic) religions. For example, Judaism, Christianity, and Islam all assume that people can freely choose to perform sinful or virtuous acts (Baumeister, Masicampo, & DeWall, 2009), though reconciling such freedom with God's omnipotence is a particularly vexing theological challenge for these religions. In other words, religion and free will have much in common. They both educe questions regarding choice, willpower, and self-control. Regardless of whether free will exists, belief in it appears to benefit society (Baumeister, Bauer, & Lloyd, 2010). Religion, by way of encouraging this belief, can improve functioning within a civilization and therefore benefit the society itself. In other words, religion may benefit individuals and society in part by supporting the belief in free will. Specifically, most organized religions encourage the belief that one can choose to resolve dilemmas by controlling selfish impulses and thoughts that might cause harm to oneself or others. For example, Western religions tend to encourage supporters to resist immediate temptations in favor of more substantial long-term goals, to bolster inner restraints and to curb aggressive inclinations, and to replace these with pro-social behaviors that appear to benefit society.

We have results from a pilot study that may provide insight into the links between free will and mental health in caregivers. In this study, we assessed the associations between attributions of God control and psychological distress (using the Depression, Anxiety, Stress Scale [DASS]; Lovibond & Lovibond, 1995) in 81 caregivers of patients with schizophrenia (Tuchman, Mejia, & Weisman de Mamani, 2010; described in Weisman de Mamani, Mejia, Gurak, & Sapp, 2011). We found that participants who agreed with the statement that "God controls most things that happen to us, including mental illness" reported greater distress than those who disagreed with this statement. In other words, perceiving that God controls a loved one's illness (i.e., that free will is limited) may cause distress because it suggests that even with wise choices, serious planning, and initiative, patients and caregivers do not have the power to control mental illness. Freedom and choice are deeply woven into the fabric of human relations (Baumeister, 2008) and Western societies place a high premium on them. Thus, it is not surprising that mental health may decline when perceptions of free choice and control

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are challenged or lacking. In short, religion may be useful to individuals in coping with mental illness, partially because it supports both the exercise of and the belief in free will (Baumeister, Bauer, & Lloyd, 2010).

From the literature reviewed previously, it seems that individuals with a free will perspective would be more adept at a cognitive and emotional coping style that would allow them to reframe suffering and other potential adversities in a manner that is beneficial, or at the very least, tolerable. This has important implications for caregivers of individuals with dementia. Dementia is undeniably difficult to manage and the prognosis for dementia-related disorders, such as AD, is bleak (most individuals with dementia die within 4–8 years of receiving an AD diagnosis; Thies & Blieler, 2012). However, some caregivers continue to thrive and even report benefits from the caregiving experience, such as experiencing pride in fulfilling one's obligations, a sense of growth and increased meaning and purpose in life, heightened sense of self-worth from doing a difficult job well, and satisfaction from knowing that that one's relative is getting excellent personalized care (e.g., Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Sapp, 2002). We believe that holding a free will perspective may be one factor that distinguishes these caregivers from those who languish in response to the challenging demands of caregiving. In the following text we will provide a case illustration of how a caregiver may utilize free will beliefs and religion to cope more effectively with dementia. The example is hypothetical, yet contains composites drawn from several different caregivers that we have seen over the years.

CASE EXAMPLE

Bernie, age 70, is a retired high school math teacher. Bernie is married to Wilma, age 68, who started having noticeable signs of dementia approximately eight years ago and shortly thereafter was diagnosed with Alzheimer's disease. Wilma had primarily been a homemaker and a stay-at-home mother throughout their 45-year marriage. They have two children, ages 38 and 40. Wilma volunteered frequently at Bernie's school and at their local church and had been highly involved in all of their children's school and extracurricular activities when they were growing up. Bernie and Wilma had a very close and loving marriage and did most of their hobbies together. They enjoyed gardening, attending church gatherings, and traveling. For 20 years, Bernie had been promising Wilma that he would retire at age 70 and they would commence a three-month tour "around the world." Unfortunately, as Wilma's condition worsened, Bernie began to realize that this dream was no longer viable.

Wilma was having difficulty taking care of essential household duties. She could no longer feed and bathe herself properly, and her ability to communicate was also quickly declining. Two years after the illness onset,

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Bernie felt compelled to retire from a job that he still enjoyed immensely in order to care for Wilma full-time. His children were busy with families of their own and neither lived nearby. Bernie's closest friend had died three years earlier. Although Bernie had several friends and acquaintances at church, he had stopped attending services because Wilma's increasing physical and cognitive impairments made it too difficult for him to manage taking her out alone. Bernie had always prided himself on being a strong person who was able to roll with the punches and confront life's issues head on. However, devoid of the usual day-to-day pleasures, such as interacting with students, friends, and a bright, cognitively, intact wife, Bernie began to experience a great degree of despair. He initially felt very alone, overwhelmed, and disillusioned.

After an adjustment period that lasted approximately one year, Bernie began to find meaning in the caregiving role. He drew upon attitudes taught to him by his parents and religious leaders, as well as those that he developed throughout his career. As a school teacher he liked to tell his students that "if you can't get from A to B directly, find an alternative route." He began to utilize this philosophy in responding to his current situation. He learned everything he could about Alzheimer's disease. Although he knew he could not "fix" Wilma's symptoms and that with time they were likely to worsen, he came to enjoy overcoming some of the day-to-day challenges. For example, he called upon John, a friend from his church, to help him install a chairlift for Wilma so he could get her upstairs for bed more easily in the evenings. Installing the lift himself gave him a sense of empowerment. He began to believe that with a little determination, he would be able to handle each new challenge presented by the illness. Bernie also appreciated the opportunity to work on a project with an old friend. He enjoyed John's company and found comfort in discussing his wife's illness with someone who shared his Protestant philosophy on life. John apprised other church members about Wilma's illness. Bernie was heartened and surprised by the extent to which members rallied to help. John and his wife began taking care of Wilma on two Sundays a month so that Bernie could attend worship services, and other church members frequently brought over home-cooked meals in the evenings.

Although new stressors continued to present themselves, Bernie focused his energy on the gratitude he felt for the way his fellow church members came to assist him in his time of need, and for having had so many wonderful years with his wife before her illness set in. Worshipping on Sundays reinforced Bernie's connection to God and to others and made him feel much less alone. In the mornings he found comfort in reciting the Serenity Prayer,[2] which he found immensely helpful in getting through the challenges of each day. Bernie began taking more initiative either to make life the way he wanted it, or to better accept life the way it was. For instance, although it was difficult for his children to visit as often as he would have liked, Bernie

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began calling them more frequently. They were always happy to hear from him and he enjoyed the increased contact. Bernie's son suggested that he and Wilma move closer so that he could help care for her. For the moment, Bernie still enjoys living in the home that he and his wife worked together to build, but he feels grateful for this option and plans to use it down the road should things become too much for him.

Though Bernie continues to experience moments that are emotionally and physically challenging, he now views caregiving as an opportunity rather than a chore. He values the chance to give back to the person who dutifully cared for him and his children throughout their marriage. Bernie feels that he could not have managed the stresses of caretaking without the aid of his religion, his religious community, and, most important, his increasing sense of security in knowing that he has the autonomy to choose how to appraise and react to each new situation that presents itself in regard to his wife's illness.

CONCLUSION

This article reviews the literature on religion and free will perceptions in the context of caregivers coping with dementia. Stemming from the studies reviewed above, we conjecture that caregivers who are more religious and endorse greater free will beliefs will experience lower levels of depression and anxiety and greater quality of life. They will also be in a better position to aid their loved ones with dementia more effectively. More empirical research is needed to validate these claims.

NOTES

1. This is a popular Christian motto that emphasizes the importance of self-initiative. Interestingly, although it is one of the most frequently quoted "biblical" phrases, it does not actually appear in the Bible. Credit for the phrase is often misattributed to Benjamin Franklin but it appeared earlier in the writings of Algernon Sidney. See http://en.wikipedia.org/wiki/God_helps_those_who_help_themselves
2. "God grant me the serenity to accept the things I cannot change; courage to change the things I can; and wisdom to know the difference." This prayer is attributed to the twentieth-century American theologian Reinhold Niebuhr. It is, perhaps, best known through its association with Alcoholics Anonymous.

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