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THE INFLUENCE OF RELIGION: INDIVIDUALS WITH DEMENTIA AND THEIR
FAMILY CAREGIVERS

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ABSTRACT

Religion has been cited as a positive coping mechanism for dealing with chronic illnesses and stress. However, studies yield mixed results on the relation between religion and positive outcomes for family caregivers of individuals with dementia. Moreover, research concerning religiosity of individuals with dementia has not been extensively explored. One hundred eleven individuals with mild to moderate dementia and their family caregivers were interviewed in-person to evaluate individuals with dementia's everyday-care values and preferences, including religious preferences. Using multiple regression and multi-level modeling, we examined how measures of religiosity (attendance, prayer, and subjective ratings of religiosity and its importance) influence quality of life in individuals with dementia and their family caregivers, while accounting for individual and familial characteristics. After accounting for demographic characteristics and care-related stressors, regression analyses indicate that religiosity is not significantly associated with caregivers' quality of life. However, religiosity is associated with higher quality of life in individuals with dementia. To examine the findings for individuals with dementia further, an actor-partner multi-level model was used to account for the interdependent relationship of dyads. We found that caregiver reports of the importance of religiosity to the individual with dementia were positively associated with individual with dementia self-perceived quality of life. These findings suggest that people with early-stage dementia use religiosity as a positive coping mechanism as they face a catastrophic illness. Given the dependence of individuals with dementia on caregivers to participate in religious activities, it is important that caregivers understand individuals with dementia's values concerning religion.

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Chapter 1

Introduction

As the world's population continues to age, added longevity has had the unfortunate effect of increasing the number of people who suffer from long-term morbidities such as physical limitations, chronic illnesses, and dementia (Nightingale, 2003). In 2010, there were approximately 5.3 million people afflicted by Alzheimer's disease in the United States alone—and as the baby-boomer generation continues to enter old age, this number is only expected to grow. Some estimates place the number of affected individuals at 7.7 million by 2030. With this growing number of affected individuals, there will be an even greater need and demand for caregivers to fill the role of caring for these elderly individuals (Tremont, 2011). Though there are more years of healthy aging, there also more years with disability at the end of life. Caregivers for the elderly are likely going to be providing intense care for longer periods of time (Nightingale, 2003).

Currently, as many as seventy-five percent of dementia patients receive care from a family member at home. While many caregivers report some positive effects of taking on this role—such as feeling useful and developing a positive attitude and appreciation for life—the role is demanding and often takes a toll on caregivers (Tremont, 2011). Although caregivers often step up to assume the role, doing so willingly and without complaint, they are also at increased risk for mental health problems and physical illness (Zarit, 2009). They must manage and balance their own needs with the needs of their relatives, which may subsequently lead them to make certain personal sacrifices. In addition, feelings of burden are common due to the objective requirements of providing care (such as time and physical demands) as well as subjective experiences (such as the emotional reaction to caregiving) (Tremont, 2011). However, since there are many factors that can affect the experience, there are opportunities for intervention and improved outcomes (Yap, Seow, Henderson, & Goh, 2005). Efforts to support caregivers and determine factors that can relieve feelings of burden and improve overall well-being serve two

functions: Such interventions improve quality of life for both the caregiver and the individual with dementia (Yap et al., 2005). One factor that may be used as a support for coping with the caregiving role—but has not been extensively investigated—is religion or spirituality.

Religion and Coping

In general, when people face situations over which they have little control, they can use religious beliefs to manage their feelings of being helpless and give meaning and order to the events of their lives (Katsuno, 2003). It has been suggested that suffering can lead individuals in one of two general directions—promoting spiritual growth or diminishing the state of their spirit (Katsuno, 2003). Thus, some individuals may experience spiritual pain manifested by fear, despair, and hopelessness when faced with difficult situations, while others use religious coping in an adaptive manner. In such cases, faith allows people to transcend losses associated with disease and look for positive outcomes. Faith in God can also provide a source of strength by helping individuals feel like they will never be abandoned (Stuckey, 2001). People may also say that their circumstances are part of God's plan. Moreover, belief in a higher power and hope for an afterlife can allow people to look past current difficult life circumstances to see them as manageable, since they are seen more as a temporary burden before an eternal reward. At the same time, if people do not properly reconcile negative feelings such as anger or resentment at God for the situation in which they have been placed, their religion may become a barrier to positive outcomes (Stuckey, 2001).

According to the Cognitive Theory of Stress and Coping, individuals may utilize meaning-focused coping when a resolution to a particular problem is not possible (Lazarus, 1966). When utilizing meaning-focused coping, individuals generate positive intrinsic emotions and draw on beliefs—possibly religious and spiritual values or existential goals of having a purpose in life—to self-motivate and maintain well-being, even in difficult times. Such a coping mechanism includes four general categories: positive reappraisal, revision of goals, spiritual beliefs, and infusion of normal day-to-day events with

new and positive meaning (Folkman, 2008). The Reconciled Life Perspective provides another mechanism by which religion can be helpful. This construct, proposed by Stuckey (2001), describes the connection between religion, spirituality, and well-being and examines the extent to which individuals are able to reconcile adverse events in their lives with their religious or spiritual beliefs. People with strong beliefs may draw on religion for support, but they do not expect to be protected from adverse events simply because they practice a particular religion. As such, religion is only beneficial when people do not feel abandoned by the higher power in which they place their faith and do not begin to question their beliefs simply because of an untoward event (Stuckey, 2001). Expectations that life will be free of pain and suffering reflect an inability to reconcile adverse events with one's beliefs. However, it can be difficult to account empirically for motivation to religion—some people may be intrinsically religious and use beliefs to deal with life circumstances, while others may be extrinsically religious and view religion as a means to achieve gains (Herbert, Dang, & Schulz, 2007).

In addition to these potential intrinsically generated benefits of religiosity, it is important to consider some of the indirect ways in which religion may impart improved outcomes. High religiosity may be tied to various behaviors that are related to higher well-being in general (Herbert et al., 2007). Some religions promote certain lifestyle practices, such as refraining from smoking or drinking, that have positive impacts on health (Stuckey, 2001). It is also possible that interest in religious faith and good health are independent but co-existing functions of individuals who are simply constitutionally stronger (Jolley et al., 2010). Additionally, attendance at religious services may be a proxy for other phenomena, such as a desire for social integration, which is not truly related to religion (Herbert et al., 2007). Being a member of a religious organization may introduce opportunities for assistance—including both emotional and practical support.

Religion versus Spirituality

The majority of individuals living in the United States classify themselves as either religious, spiritual, or in many cases, both. One issue is distinguishing between the two constructs. And yet, it would seem that such a distinction is difficult to make, as most individuals see both constructs as being inextricably linked and essentially synonymous. In fact, the association between religion and spirituality often lies within the individual himself. Typically, religion refers to the sociocultural program for applying and practicing ones spiritual propensities. Spirituality, then, refers to the inner experiences that arise from putting religion into practice. Spirituality can also refer to beliefs and practices that connect people with meaningful experiences that go beyond themselves, while religion is seen as a doctrinal framework that allows for beliefs and practices to be guided by participation in a broader community (Stuckey, 2001). In essence, spirituality is often used as a broader term that encompasses a variety of experiences that may or may not include a specific religion or practice (Atchley, 2009). So, it would seem that religion places a greater emphasis on worship in a communal sense, whereas spirituality is more of a personal experience (Stuckey, 2001). At the same time, a large majority of people view themselves as both spiritual and religious, while a smaller minority see themselves as spiritual and not religious (Atchley, 2009).

Measuring Religiosity

In examining the measurement of spirituality and religion in research, it becomes evident that many measurements of spirituality in fact are truly measuring religiosity (Atchley, 2009). Studying the effects of religiosity in research is best accomplished by using constructs that encompass various dimensions of religiosity; however, many studies in the past have simply focused on one or two aspects of religiosity, which can be somewhat misleading (Krause, 1998). Several measures capture most of the dimensions of religiosity: Organizational religiosity addresses formal religious involvement, such as

attending formal church services or events at a place of religious worship. Non-organizational religiosity addresses private religious practices, which include praying or reading religious texts in private. Both constructs capture different elements of religiosity, and examining one without the other does not provide for a complete picture due to the high correlation among different factors (Krause, 1998). Subjective assessment of the degree of religiosity is a third commonly examined construct, which addresses internal feelings (Leblanc, Driscoll, & Pearlin, 2004). Other less studied dimensions of religiosity include ideological, intellectual, ritual, experiential, and consequential (Faulkner and DeJong, 1966). Of additional importance in examining the role of religiosity specifically as a coping mechanism is the ability to directly examine whether participants state that they use prayer or support from God when dealing with difficult times and stress (Krause, 1998). More specific religious coping scales distinguish the extent to which individuals rely on God for support. One such scale, utilized by Schaefer & Gorsuch (1993), characterized individuals as utilizing collaborative, self-directing, or deferring styles. In the collaborative styles, individuals indicate that they work with God to solve problems and deal with difficult situations. Self-directing individuals rely solely on themselves and act to deal with and solve their problems independent of input from God. Finally, deferring individuals stated that they surrendered their problems and troubles to God, expecting that God would provide the solution.

In general, it is difficult to obtain highly specific measures of religiosity related to the caregiving role, but some scales have been developed to delve deeply into this topic. A scale utilized by Pearlin and colleagues provides an ideal example of distinguishing between the many facets of religiosity. First, it is one of few scales that make a distinction between religiosity and spirituality in asking individuals to rate both how religious and spiritual they consider themselves to be. The scale includes aspects of non-organizational and organizational religiosity, inquiring how often caregivers attend church services as well as how often they pray. What makes the scale truly unique is the depth the questions address as to why caregivers pray, including the following: strength to go on giving care, strength to control feelings when they get upset, to show their faith, to end their relative's suffering, to end their own suffering, for guidance in providing the best care, to become a better person, for guidance in making the best decisions,

for inner peace, for forgiveness for thoughts and actions, to give thanks for support from others, to give thanks for being able to serve as a caregiver, and for God's will to be done. Furthermore, the scale inquires whether caregivers are able to attend religious services as often as they like. The detailed questions regarding why caregivers pray allows for insight into the intrinsic motivation for religiosity, which is useful in distinguishing between individuals who seek support through prayer and individuals who seek a solution. Furthermore, reports on whether the caregivers would like to attend services more often allows for a conclusion regarding why attendance at services is often unrelated to frequency of prayer and personal practice measures. Specific measures of religiosity and religious coping provide for research that is less ambiguous in findings. More targeted scales and constructs can help untangle inconclusive findings regarding potential positive, neutral, and negative effects of religiosity, as it is often difficult to conclude why individuals engage in religious activities without such questions. As such, it may be that individuals who pray for support rather than a solution experience positive outcomes, while those who expect improved outcomes, simply because they have high levels of religiosity, experience the negative outcomes.

Religiosity and its Positive Influence on Caregivers

The role of religiosity in the lives of caregivers has been studied using different constructs and examining various outcomes. Consequently, it is difficult to untangle the true influence of religiosity on outcomes in caregivers and it is important to be aware of the potential positive and negative influences. The importance of religion is cited by most caregivers, and the majority report that they pray nearly everyday and perceive religion to be important. However, less than half report attending religious services. As such, among caregivers, non-organizational religion and subjective religiosity have been moderately correlated but organizational religion is not correlated with either facet of religiosity (Herbert et al., 2007). Attendance at religious services in caregivers is related to better well-being, but the extent to which spiritual needs are met is actually a better predictor of well-being and mental health (Burgener,

1994). In the Alzheimer's disease caregiving experience, religion can be helpful through the supportive role of the church. Parishioners and clergy may offer instrumental support to the caregivers or act as advocates to link them up with healthcare providers and social services. As such, the church can emphasize the importance of seeking help from the right individuals (Stuckey, 2001). Churches can potentially provide caregivers with an emotionally supportive environment (Leblanc, Driscoll, & Pearlin, 2004). Interestingly, in examining current caregivers and bereaved caregivers, religious attendance tends to increase after the death of the individual with dementia, while prayer and intensity of belief stay the same. This suggests that the caregiving role itself limits the caregivers' ability to attend religious services (Stuckey, 2001). In the same vein, caregivers have been found to attend church less frequently when dementia patients are living with them, so it is possible that due to the close relationship between social and religious activities, caregivers could consequently have less social support (Burgener, 1994). Changes in religious participation over time may simply reflect changing abilities and needs, rather than changes in beliefs (Burgener, 1994).

Studies concerning religion's effect on caregivers have examined a variety of outcomes. Religiosity on several dimensions—organizational, non-organizational, and subjective—is associated with lower depressive symptomatology, even after controlling for physical health, burden, and social integration (Herbert et al., 2007). Higher levels of spiritual well-being are associated with lower burden scores, reflecting the idea that religion/spirituality may allow individuals to interpret the experience as less burdensome (Spurlock, 2005). Qualitative research shows that caregivers express the importance of religion/spiritual experiences when coping with their role, and they often cite prayer and the idea that God has a plan for them as sources of coping and comfort. They also express a belief that you cannot have expectations that God will make life easier simply because you pray or follow a particular religion. These findings emphasize the point that optimism and self-reliance are important qualities in drawing positive outcomes from religion (Stuckey, 2001).

Religiosity and its Negative Influence on Caregivers

As discussed, religious beliefs can be detrimental to health if they produce feelings of guilt, self-doubt, shame, and low self-esteem in the caregiver. Religiosity has been shown to be unrelated to feelings of stress in caregivers, including both primary objective stress and primary subjective stress (LeBlanc et al., 2004). However, within the same sample, feelings of role overload were actually correlated with higher self-perceived religiosity among caregivers with personal health problems. This association between role overload and religiosity suggests that caregivers were using religiosity as a coping mechanism; however, the coping did not decrease harmful effects of stress. (LeBlanc et al., 2004). Increased church attendance has also been positively associated with more psychological distress (Cohen, Teresi, & Blum, 1994) and lower self-rated health (Haley, 1987). A study specifically using a religious coping scale shows that religious coping is associated with worse overall physical health in caregivers but is not associated with depression (Mausbach, Coon, Cardenas, & Thompson, 2003). Examining religious coping activities, in terms of both positive and negative coping practices, shows that religious discontent is associated with greater burden and depression (Shah, Snow, & Kunik, 2001).

African Americans and Caregiving

Qualitative caregiver reports show that many reported that their ethnic background influences their caregiving practices, and many reported that their religious beliefs shaped how they approached the caregiving role (Nightingale, 2003). African American caregivers tend to display differing patterns of care, and they display higher scores on traditional caregiving ideologies. They seem to derive greater overall satisfaction from serving in the role and see the role as less of an intrusion. Due to their cultural background, they demonstrate unique patterns of assistance. They report that caregiving is a traditional family value and the role is something they can feel good about (Sterritt & Pokorny, 1998). Additionally, they consistently report that God/religion is their primary source of social support, and church

participation carries a special significance in their lives, given that they sacrifice many other social activities to serve in the caregiving role (Sterritt & Pokorny, 1998). African Americans report higher spiritual well being and lower caregiver burden compared to Caucasians (Spurlock, 2005), while Caucasians tend to report more depression and view the caregiving experience as being more stressful (Janevic & Connell, 2001). Though both groups share similar religious practices and view spirituality and religion as important aspects of their caregiving, it is possible that African Americans differ in how they interpret the meaning of their experience (Paun, 2004). African American caregivers of Alzheimer disease patients are more likely to rely on pastors/church for the support (Nightingale, 2003). At the same time, some qualitative studies report that African-Americans are more likely to conceal the patient from the church community, as they want to keep the illness private (Levkoff, Levy, & Weitzman, 1999).

Overall Conclusions Regarding Religiosity for Caregivers

Many studies have examined the link between religion/spirituality and negative outcomes, but it is important to consider positive outcomes as well (Herbert et al., 2007). As demonstrated, quantitative studies have utilized many different scales, constructs, and outcomes, which may contribute to the variability in findings of religion being a positive, negative, or neutral force in caregivers' lives. Additionally, some findings may seem ambiguous or contradictory due to differences in study design that make it difficult to determine the direction of certain associations that have been found. For example, while increased church attendance is linked to some negative outcomes, the possibility exists that people who require more help are seeking more help. Future studies should be designed with such ideas in mind to provide for the best model of religious influence. Nonetheless, qualitative results seem to consistently show that caregivers cite religion as an important coping resource. It is possible that one of the major distinctions lies in how caregivers interpret the religious experience, and it is also possible that the other factors (such as stress) are simply too overwhelming for religion to be meaningful.

Religiosity and its Influence on Individuals with Dementia

Most individuals consider themselves to be religious, especially in old age, and yet the needs and interests of dementia patients have been neglected, both in research and in health care (Doherty, 2006). Initial research suggests that individuals with mild to moderate dementia may even demonstrate higher levels of average religious activity and intrinsic religiosity than other older adults (Katsuno, 2003), further emphasizing the need to investigate the implications of these beliefs in greater detail. It shouldn't be assumed that people with dementia simply cannot be reached in a spiritual domain (Snyder, 2003). Examining religion is another aspect of the person-centered dementia approach that should be prioritized: It is important for the individual to maintain personhood, even in the face of a disease that impinges such cognitive impairment. This may include maintaining religious beliefs and spirituality (Doherty, 2006). Understanding the spiritual needs of individuals with dementia is important, as many of them likely have to approach spirituality and practice differently, due to the changes they experience in cognitive ability and personality (Doherty, 2006). Discussing the challenges to come could be valuable, as individuals with dementia would have the opportunity to express the importance of religion, and the responsibility would then be on the caregivers to honor those wishes when the individuals may no longer be able to articulate their desires (Snyder, 2003).

Qualitative studies show several themes associated with spiritual needs of people with dementia: to be connected, to be respected, to be loved, to be accepted, to be compassionate, to share, to be productive, and to still have hope (Doherty, 2006). Some qualitative studies highlight major themes regarding the role of religion in Alzheimer's: finding meaning in Alzheimer's, coping with the effect of Alzheimer's of faith, and conveying the effect of Alzheimer's on religious practice (Snyder, 2003). Some people view the disease as being part of God's plan, and they feel that religion plays a role in helping them see the inevitability of mortality. They also find that religion gives a general sense of hope, a sense of hope in the afterlife, feelings of acceptance, and relieved anxiety regarding fear of death (Snyder, 2003). When looked at in a positive light, religion can provide a way to understand problems related to

the daily struggles associated with the disease (Snyder, 2003). Other people struggle with feeling conflicted over whether or not they are being punished by God. They may experience a sort of crisis and question their religious practice, or they may feel disillusioned with unanswered prayers (Snyder, 2003). The somewhat ambiguous results that have been found could be due to the wide range of ways in which religiosity is interpreted in difficult situations.

Religious communities can provide support, but specific aspects such as prayer and worship can provide additional benefits beyond social interplay (Jolley et al., 2010). Qualitative studies have been used more extensively in examining the role of spirituality in the lives of individuals with dementia, but they have shown that exclusion from faith communities can lead to suffering, and some older individuals felt that their churches treated them with less support and warmth than would be expected (Jolley et al., 2010). In early stages of dementia, there is no reduction of spiritual awareness, and findings do not suggest that individuals lose spirituality at this stage of dementia (Jolley et al., 2010). Generally high scores of religiosity are reported, but this is to be expected because spirituality generally increases with age (Jolley et al., 2010).

Though quantitative studies have been rare with people with dementia, one study examined both qualitative and quantitative effects of religiosity (Katsuno, 2003). Religiosity was measured in terms of both organized and non-organized religion, as well as subjective values and beliefs. Qualitative results from the study expanded upon basic themes and provided information as to how individuals with dementia interpret religion. Religious beliefs generally continue in the form of strong faith. Support from God is seen as an important facet of religion, as individuals look to God for strength, security, and comfort, and some indicate that they feel as though God is someone they can always turn to for help and protection. At the same time, individuals express feelings that private religious practice tends to become more important, as they experience changes that limit their attendance at religious activities. In addition, while some are able to attend church and participate in social meetings at church, they need support from others and assistance from family in order to do so. Finally, some individuals report decreased frequency of church attendance due to a lack of physical energy. Doubts in faith may also arise as a result of

emotional and physical stress (Katsuno, 2003). This study was one of few quantitative studies that have been conducted, and it shows a correlation between total religiosity scores and higher quality of life in individuals with dementia. Though the results are less generalizable due to a small sample size, the study provides support for further investigating preferences in a quantitative manner is important. Such research could be helpful in guiding educational programs for healthcare practitioners (Katsuno, 2003).

Overall Conclusions Regarding Religiosity for Individuals with Dementia

Based on the initial studies pertaining to religiosity and its potential influence for individuals with dementia, future studies seem to be warranted. The existing literature is comprised primarily of qualitative and correlational studies, so it would be informative to investigate these factors through other study designs and analyses to draw stronger conclusions. Regression based analyses of cross-sectional data could be one starting point, but longitudinal studies may be the best way of evaluating long-term effects of religiosity.

Future Directions

The dyad of the caregiver and the individual with dementia consists of two people, and as such, it is important to realize that the perspectives of both individuals are key in obtaining a holistic viewpoint and understanding of how the quality of life can be improved for both members of the dyad (Lyons & Sayer, 2010). Examining perspectives of both individuals provides the opportunity to look at the relationship as a dynamic process of bidirectional interactions. The cyclic trend, of the caregiver influencing the care receiver and the care receiver in turn influencing the caregiver within a single context, demands the use of specific analytic procedures such as multi-level modeling that can account for the intrinsic qualities of the dyadic relationship (Lyons & Sayer, 2010). While the majority of statistical

analyses assume independence of data, multi-level modeling accounts for shared variance in a dyad, making it a valuable statistical method for analyzing data of individuals in a dyad (Lyons & Sayer, 2010).

In this study, quantitative analyses will be conducted to investigate the role of religiosity in the lives of caregivers and individuals with dementia, given that previous qualitative studies show that both groups cite religion as a positive coping mechanism in their lives. The first goal of this study is to examine and compare religious profiles of individuals with dementia and their caregivers. It is hypothesized that individual facets of practice including organizational religion versus non-organizational and subjective religiosity will not be correlated. However, caregivers and individuals with dementia will demonstrate similar religious practices. We also hypothesize that caregivers will accurately report on the religiosity of individuals with dementia. African American caregivers will report higher levels of religiosity compared to non-African American caregivers. Next, we will determine if religiosity plays a unique role in predicting quality of life, after controlling for demographics and care-related factors. It is hypothesized that higher religiosity will be associated with higher quality of life in both individuals with dementia and their caregivers. Finally, we will examine how the caregivers' personal religiosity and understanding of their relatives' religiosity affects quality of life for the individuals with dementia, given their level of dependence on caregivers for certain aspects of practice. It is hypothesized that higher caregiver religiosity and higher endorsement by the caregiver regarding importance of religiosity to the individual with dementia will predict higher quality of life as reported by the individual with dementia. The same effects will be seen for caregiver reports of individual with dementia quality of life.

Chapter 2

Methods

Participants

Dyads or respondent pairs ($N = 111$), consisting of an individual with mild to moderate dementia and his or her informal spouse or child caregiver, were recruited from two different sites. The Family Caregiver Alliance (FCA) is located in the San Francisco Bay Area and serves a population of caregivers and families who primarily provide care and support for individuals with adult-onset brain diseases and disorders. Using FCA client lists of six counties in the San Francisco Bay Area, a convenience sample of dyads was identified consisting of caregivers and their impaired relatives. The second site, the Community/In-Home Services department of Benjamin Rose Institute on Aging (BR) is located in Cleveland, Ohio. This department provides service to older adults in need of home aide, nursing services, or adult day care. Case managers at BR helped to identify clients who were suffering from cognitive impairment, and those clients were subsequently contacted regarding the study. Both the FCA and BR also utilized community outreach and other local service agencies to recruit additional respondents. Given the nature of the sites used to recruit participants, the population from which this sample is drawn tends to be representative of those family caregivers who are characterized as “help seeking.” This is similar to other caregiving studies that also utilize convenience samples (Aneshensel, Pearlin, Mullen, Zarit, & Whitlatch, 1995).

Caregivers were predominantly women (81.1%, $n = 90$), aged 30 to over 90 ($M = 61.2$ years, $SD = 14.0$; as per the request of the Institutional Review Board, ages above 90 years were recoded to 90 in order to minimize identification of specific individuals based on their age). Caregivers were identified as either a spouse/partner (40.5%, $n = 45$) or not a spouse/partner (59.5%, $n = 66$). Over half of the caregiver

sample (52.3%, $n = 58$) was African American. About half of the individuals with dementia were women (53.2%, $n = 59$). Religious affiliation of the caregiver sample was primarily Protestant (57.7%, $n = 64$), but there were also Catholics (10.8%, $n = 12$), Jews (5.4%, $n = 6$), Christians (2.7%, $n = 3$), and other (22.5%, $n = 25$). Individuals with dementia were between the ages of 39 and over 90 years of age ($M = 76.8$, $SD = 8.9$). About half of the individual with dementia sample (46.8%, $n = 52$) was African American (see Table 1). Religious Affiliation of the individual with dementia sample was similarly distributed, with the majority indicating Protestant religion (55.0%, $n = 61$). Catholics (14.4%, $n = 16$), Jews (6.3%, $n = 7$), Christians (6.3%, $n = 7$), and other (15.3%, $n = 17$) were also represented.

Table 1: Characteristics of Caregivers and Individuals with Dementia

	<i>M</i>	<i>SD</i>	Range
<i>Caregivers</i>			
Age	61.2	14.0	30-90+
Female (<i>yes</i> = 1)	0.81	0.39	0-1
Spouse (<i>yes</i> = 1)	0.41	0.49	0-1
African-American (<i>yes</i> = 1)	0.52	0.50	0-1
Education	4.0	1.2	1-6
Care-related Stress	19.9	16.0	0-72
Loss of Self	1.5	0.67	1-4
Overload	2.0	0.77	1-4
Total Religiosity	4.2	1.4	0-6
Importance of Religiosity to IWD reported by CG	3.5	2.5	0-6
Quality of Life	2.9	0.47	1.83-3.92
<i>Individuals with Dementia</i>			
Age	76.8	8.9	39-90+
Female (<i>yes</i> = 1)	0.53	0.50	0-1
African-American (<i>yes</i> = 1)	0.48	0.50	0-1
MMSE score	20.7	3.8	13-26
Education	3.2	1.5	1-6
Total Religiosity	3.7	1.5	0-6
Importance of Religiosity to IWD reported by IWD	4.5	2.2	0-6
Quality of Life	2.7	0.43	1.77-3.85

Procedures

Both the San Francisco and Cleveland sites followed the procedures described as follows, and any differences are noted. Rates of eligibility and screening were similar across both sites and are presented for the entire sample as a whole.

In order to be eligible to participate in the study, a family caregiver had to meet certain criteria: a) be a primary caregiver (meaning he or she was the person most involved in providing assistance and daily care to the individual with cognitive impairment); and b) be a spouse or adult child (FCA sample) or a relative or friend that identified as the caregiver (BR sample) for the individual with cognitive impairment. The individual with cognitive impairment had to meet the following criteria: a) have a confirmed diagnosis from a physician of an adult-onset brain disease or disorder (FCA sample) or symptoms of behavior problems (BR sample); b) be living at home (meaning he or she was residing in the community rather than an institutional setting); and c) have mild to moderate cognitive impairment as defined by scores ranging from 13 to 26 on the Folstein Mini-Mental State Exam (MMSE). This range was selected based on previous research suggesting that individuals with early-stage cognitive impairment will score between 23 to 26 (indicating mild cognitive impairment) or between 18 to 22 and 13 to 17 (indicating moderate to more severe cognitive impairment) (Whitlatch, 2005). About one-third (32%, $n = 55$) of the 173 individuals with cognitive impairment who met the initial criteria for inclusion in the study were subsequently ineligible due to scores on the MMSE. Approximately one-third (33%, $n = 18$) of those who were ineligible obtained a score less than 13 on the MMSE, while the other two-thirds (67%, $n = 37$) scored above 26 on the MMSE. In addition, 5 individuals with cognitive impairment did not successfully complete the written-consent process or declined to continue with the study after completing a partial interview and 2 dyads were used in pretesting procedures. As a result, the final sample of 111 individuals with cognitive impairment and 111 family caregivers was obtained.

Each member of the dyad completed two separate, in-person interviews at time points approximately two years apart. The purpose of the interviews was to evaluate everyday care values and

preferences of the individuals with dementia. Visual aids were utilized for response choices in order to minimize burden on memory for all participants. Thirty-four cases dropped out between Time 1 and Time 2 due to general attrition ($n = 32$) and failure to participate in the interview ($n = 2$).

Measures

Demographics.—Sociodemographic characteristics were obtained for both the individual with dementia and the caregiver, including age, gender, race, highest level of education, employment status, and income. *Race* was coded 1 for African-American and 0 for others. *Education* ranged from 1 (*less than high school*) to 6 (*postgraduate degree*). The relationship between the caregiver and individual with dementia was coded 1 as spouse and 0 for others. Final analyses included only variables that were not highly intercorrelated: race, relationship, and education (i.e., income and gender were highly related to education and relationship respectively).

Dependent Measures.—The Quality of Life—Alzheimer’s Disease Scale (Logsdon, Gibbons, McCurry, & Teri, 1999) is a 13-item questionnaire that was designed in order to provide a report of individual with dementia quality of life. The scale uses simple and straightforward language in order to facilitate its use by individuals with cognitive impairment. Items are rated to determine an individual’s current quality of life. The specific items on the scale were chosen in order to address Lawton’s four domains of quality of life in older adults (Logsdon, Gibbons, McCurry, and Teri, 2002). In this study, caregivers completed 2 questionnaires at Time 1: one regarding their own personal quality of life and the second questionnaire regarding their relative’s quality of life. Individuals with dementia completed the same questionnaire at Time 1, but only in regards to their own personal quality of life. Items were ranked on scale from 1 (poor) to 4 (excellent). Respondents were instructed as follows: “*I want to ask you some questions about your [RELATIVE’S] quality of life and have you rate different aspects of her/his life using one of four words: poor, fair, good, and excellent. When you think about your [RELATIVE’S] life, there are different aspects, such as her/his physical health, energy, family, money, and others. I’m going to ask*

you to rate each of these areas. We want to find out how you feel about your [RELATIVE's] current situation in each area. If you are not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess." The thirteen items evaluated include the following: *physical health, energy level, moods/spirits, living situation, memory, family and relationship with family members, marriage (for those who have a living spouse/partner) or closest relationship (for those without a living spouse/partner), relationship with friends, self as a whole, ability to do chores, ability to do things for fun, current financial situation, and life as a whole.* The mean score of the thirteen items was computed as an indicator of perceived quality of life, with higher computed scores indicating greater perceived quality of life (CG self-reported quality of life: $N = 111$, $\alpha = 0.86$, $M = 2.85$, $SD = 0.47$; IWD self-reported quality of life: $N = 110$, $\alpha = 0.86$, $M = 2.66$, $SD = 0.43$; CG report of IWD quality of life: $N = 111$, $\alpha = 0.80$, $M = 2.37$, $SD = 0.46$).

Independent Measures.—In addition to previously described sociodemographic variables, the independent measures tested are described below.

Individual with Dementia's Cognitive Functioning.—In order to assess global cognitive functioning, individuals with dementia completed the Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975) at Time 1. Establishing a quantitative assessment of cognitive performance is important in evaluating psychiatric patients in a standardized manner. Many clinical tests were established for this purpose, but elderly patients—especially those suffering from dementia—have difficulty cooperating with such tests for extended periods of time. For this reason, the Mini-Mental State Examination was developed as a simplified version of such examinations to assess cognitive aspects of mental functioning and disregard questions concerning aspects of mood and abnormal mental experiences. The MMSE requires only 5-10 minutes for administration and consists of eleven questions. The exam is divided into two separate sections: The first requires only verbal responses and assesses orientation, memory, and attention with a maximum possible score of 21. The second section tests the participant's ability to name objects, follow verbal and written commands, write a sentence upon command, and copy a complex polygon with a maximum possible score of 9. The maximum total score is

a 30. In this sample, the mean MMSE score was 20.74 ($SD = 3.80$). Lower scores indicate a greater degree of cognitive impairment.

Behavior Problems.—Caregivers completed a thirty-two item checklist at Time 1 to evaluate the types of memory-loss associated problems the individual with dementia exhibited. This checklist was modeled after the Revised Memory and Behavior Problems Checklist (Teri et al., 1992), but this version also includes items that address problems with activities of daily living (ADL). These items were included in the original Memory and Behavior Problems Checklist (Teri et al., 1992) and the Weekly Record of Behavior (WRB) (Fauth, Zarit, Femia, Hofer & Stephens, 2006) along with its daily version, the Daily Record of Behavior (DRB) (Fauth et. al., 2006). Adding these problems yields a more complete evaluation of the stressors that caregivers may be encountering, even in early dementia. The problems fall into three subcategories: memory-related, depressive, and disruptive behaviors. Examples of problems evaluated include the following: Asking the same question over and over; Appears anxious or worried; Arguing, irritability, and/or complaining. Items were first ranked according to how often the behavior occurred during the past week on a scale from 0 (never occurred) to 4 (daily or more often). If the behavior was endorsed as having occurred, the caregiver ranked how bothersome or upsetting it was on a scale from 0 (not at all) to 4 (extremely). The total care-related stress scale was computed by taking the sum score of the 32 Memory and Behavior Problem Stress Ratings. The mean rating was 19.9 ($N = 110$, $\alpha = 0.86$, $SD = 16.0$). Higher scores indicate higher overall levels of behavior problems.

Loss of Self.—Caregivers completed two items on a Loss of Self scale (Pearlin et al., 1990) at Time 2 in response to a question of “*To what extent do you feel that you personally have lost the following*” : a sense of who you are and an important part of yourself. Responses ranged from 1 (not at all) to 4 (completely). The scale addresses aspects of secondary strain, in which effects from the caregiver role exhibit spillover. The scale therefore measures the ways in which the caregiver role can cause stress in other areas of life. Loss of Self is a component of Intrapyschic Strain, as identified in the caregiving stress process model (Aneshensel , C. S., Pearlin , L. I., Mullan , J. T. Zarit , S. H. Whitlatch , C. J.,

1995). The mean score of both items was computed ($N = 76$, $\alpha = 0.81$, $M = 1.49$, $SD = 0.67$). Higher scores indicate higher feelings of loss.

Overload.—Caregivers evaluated feelings of role overload at Time 1 by completing four items related to levels of energy and how much time it takes to do the things they need to do. Statements include the following: *You are exhausted when you go to bed at night; You have more things to do than you can handle; You don't have time just for yourself; You work hard as a caregiver but never seem to make any progress.* Responses were coded on a 4-point scale ranging from 1 (not at all) to 4 (completely). The mean score of all four items was computed ($N = 76$, $\alpha = 0.69$, $M = 2.04$, $SD = 0.77$). Higher scores indicate higher feelings of overload.

Total Religiosity.—Caregivers and individuals with dementia both responded to questions pertaining to their religious or spiritual beliefs and practices. In response to the questions of “*How often do you attend religious services?*” and “*How often do you pray or meditate on your own?*” respondents gave an answer on a scale of 0 (never) to 6 (nearly every day (4 or more times/week)). In response to the question “*How religious or spiritual would you say you are?*” respondents gave an answer on a scale from 1 (not at all religious/spiritual) to 4 (very religious/spiritual). Items were recoded to the same scale and a mean score of report of three items was computed as a total score of religiosity for both the caregiver and the individual with dementia (Caregiver: $N = 111$, $\alpha = 0.71$, $M = 4.17$, $SD = 1.36$; IWD: $N = 111$, $\alpha = 0.66$, $M = 3.69$, $SD = 1.49$).

Importance of Religiosity.—The Values and Preferences Scale (Whitlatch et al., 2005) was developed as a 37-item scale that assesses values and preferences in care for individuals with dementia. In accordance with a dyadic perspective, both the individual with dementia and the caregiver independently completed the survey to rate the importance of values and preferences in the individual with dementia care. Items were rated from 1 (not at all important) to 3 (very important). In this study, we used only 1 item from the scale, under the Self-Identity category. This item asked participants “*How important is it for your [RELATIVE] to be able to practice her/his religious or spiritual beliefs?*” Since the scale was completed by both the caregiver and the individual with dementia, the item gives the importance of

practice for the individual with dementia, as reported by the individual with dementia him or herself and by the caregiver. The mean rating of importance of practice for the individual with dementia as reported by the individual with dementia was 2.49 ($N = 108$, $SD = 0.74$) and the mean rating as reported by the caregiver was 2.16 ($N = 110$, $SD = 0.84$).

Data Analysis

SPSS version 20 was used for data entry and analyses. First descriptive analyses were run to examine the distributions in the data and the mean differences between individuals with dementia and their caregivers in religiosity variables of interest, via means and correlations. T-tests were then completed to examine the between group differences by race, caregiver/IWD, and religious affiliation. Next, we ran two sets of multiple linear regression to examine the effects of demographic variables, stressors, and religiosity on the self-reported quality of life for both caregivers and individuals with dementia. For caregivers, Model 1 included demographic variables of race (African America), relationship (spouse), and education. Model 2 added care-related stressors to include stress related to behavior problems, loss of self, and role overload. Model 3 added a final variable of self-reported total religiosity. For individuals with dementia, Model 1 included the same set of demographic variables as used for caregivers. Model 2 added the MMSE. Model 3 added the variable, self-reported total religiosity.

To further examine the relationship of factors related to individual with dementia quality of life, SAS was used for multilevel modeling (SAS PROC MIXED; Littell, Milliken, Stroup, & Wolfinger, 1996). This technique accounts for the fact that individual observations by caregivers and individuals with dementia are nested within dyads. With multi-level modeling, the dyad is the unit of analysis which is analyzed at two levels, within-dyad differences and between-dyad differences. We utilized a two-intercept model to account for the intercept (level) and slope effects for each dyad member.

More specifically we ran a series of multi-level models on the outcome variable of each person's reports of the individual with dementia's quality of life (i.e., the caregiver's perception of individual with

dementia quality of life and the individual with dementia self-report of their own quality of life). The main goal of the analyses was to look at the effects of “within-dyad” religiosity variables as reported by both caregivers and individuals with dementia on the outcome of perception of individual with dementia quality of life, rather than between-dyad variables. As a result, we first ran Model 1 an unconditional means model to examine the amount of “interdependence/similarity” within dyads. Higher ICC indicated higher levels of similarity within a dyad. The means, variances, and covariances may differ across the distinguishing variable. To calculate the ICC of distinguishable dyadic data, we control the (between-dyad) effect of relation (caregiver and individual with dementia), so that the ICC shows how similar dyadic members are, after controlling for an “average” difference between caregiver and individual with dementia.

Then in Model 2 we controlled for the “between-dyad” variables: relationship of the caregiver to the individual with dementia (spouse or other relation), race (African American or other), cognitive ability of the individual with dementia at time 1, caregiver’s experience of stress related to behavior problems at time 1, caregiver’s experience of loss of self at time 3, caregiver’s experience of role overload at time 3, and a within-dyad level of education. To simplify the model, only those control variables that were significant were retained (i.e., models only retained stress related to behavior problems at time 1 and loss of self at time 3).

We then examined more specifically the actor and partner effects of religiosity variables on the outcome. This actor-partner interdependence model takes into account the intrinsic interdependence that comes with a relationship such as that between the caregiver and the individual with dementia. Both individuals influence each other in various facets of life, such as emotion and behavior (Cook & Kenny, 2005). The actor effects in this model measure the impact a person has on his or her own outcome (individual with dementia’s impact on his or her self-reported quality of life and caregiver’s impact on his or her perception of the individual with dementia’s quality of life). The partner effects then measure the impact a member of a dyad has on the outcome of his or her partner (individual with dementia’s impact on caregiver’s perception of individual with dementia quality of life and caregiver’s impact on the

individual with dementia's self-reported quality of life). Two predictors, or within-dyad variables, were reported by both the caregiver and the individual with dementia: each individual's respective total religiosity and the importance for the individual with dementia to practice religious or spiritual beliefs. Thus, to account for the effect of one's own reports of these constructs on their own perceptions of individual with dementia quality of life, variables were entered into the model at Level 1.

Finally for Model 4, we sought to address the following questions: what are the effects of the partner's reports of religiosity variables on one's own perception of individual with dementia quality of life? Specifically what are the partner effects of reports of religiosity on individual with dementia quality of life reports after accounting for one's own reports of religiosity on perception of individual with dementia quality of life? Do caregivers' perceptions of religiosity affect either their perceptions or individuals with dementia's self-perceptions of quality of life or do individuals with dementia's perceptions of religiosity affect caregivers' perceptions of individuals with dementia's quality of life? We added in the religiosity variables to represent the partner effects of religiosity at Level 1.

Following the initial multi-level models, we ran a one-intercept post-hoc analysis to examine the significance of differential effects on the outcome for individuals with dementia and caregivers (i.e., to determine if a significant effect by the caregiver is significantly different than the effect for the individual with dementia). We also examined the effects of both religiosity variables independently.

Chapter 3

Results

Correlations

Correlations among variables of interest were examined for caregivers (Table 2) and individuals with dementia (Table 3) to understand how they were related to one another. We found that total religiosity was significantly related to race, relationship, and education for both caregivers and individuals with dementia. Total religiosity was positively correlated to being African American, while it was negatively correlated with being a spouse and having a higher level of education.

Table 2: Correlations Among Variables for Caregivers

	1	2	3	4	5	6	7	8	<i>M</i>	<i>SD</i>
1: Race(African-American)	--								0.52	0.51
2: Relationship (Spouse)	-0.50**	--							0.41	0.49
3: Education	-0.38**	0.18	--						4.05	1.21
4: Stress	-0.21*	0.11	0.08	--					19.88	16.04
5: Loss of Self	-0.30**	0.18	0.15	0.19	--				1.49	0.67
6: Overload	0.00	0.03	-0.02	0.03	0.20	--			2.04	0.77
7: Total Religiosity	0.39**	-0.30**	-0.33**	-0.06	-0.02	-0.09	--		4.17	1.36
8: Quality of Life	-0.03	0.10	0.17	-0.29**	-0.26*	-0.34**	0.07	--	2.85	0.47

*Note: N = 75; *p < .05, **p < .01*

Table 3: Correlations Among Variables for Individuals with Dementia

	1	2	3	4	5	6	<i>M</i>	<i>SD</i>
1: Race (African-American)	--						0.48	0.50
2: Relationship (Spouse)	-0.40**	--					0.41	0.49
3: Education	-0.43**	0.50**	--				3.16	1.49
4: MMSE	-0.18	0.18	0.11	--			20.74	3.80
5: Total Religiosity	0.19*	-0.27**	-0.24*	0.04	--		3.69	1.49
6: Quality of Life	-0.26**	0.28**	0.33**	0.11	0.06	--	2.66	0.43

Note: $N = 103$; * $p < .05$, ** $p < .01$

The first hypothesis predicted that correlations among individual religiosity variables would be consistent with previous findings that for caregivers, subjective appraisal and non-organizational religiosity are correlated while organizational religiosity is not correlated with either dimension (Herbert et al., 2007). These findings were not supported for individuals in this sample. For caregivers, subjective appraisal and frequency of prayer (indicative of non-organizational religiosity) were correlated ($r = 0.61$, $p < 0.001$), but attendance at church services (indicative of organizational religiosity) was correlated with both subjective appraisal ($r = 0.32$, $p < 0.001$) and frequency of prayer ($r = 0.39$, $p < 0.001$) (Table 4). For individuals with dementia the same pattern existed. Subjective appraisal and frequency of prayer were correlated ($r = 0.62$, $p < 0.001$). Attendance at church services was correlated with both subjective appraisal ($r = 0.30$, $p < 0.01$) and frequency of prayer ($r = 0.28$, $p < 0.01$) (Table 5).

Table 4: Correlations Among Individual Facets of Religiosity for Caregivers

	Subjective Appraisal	Frequency of Prayer	Attendance at Religious Services	<i>M</i>	<i>SD</i>
Subjective Appraisal	--			4.64	1.46
Frequency of Prayer	0.61***	--		5.22	1.80
Attendance at Religious Services	0.32***	0.39***	--	2.67	1.88

Note: $N = 75$; * $p < .05$, ** $p < .01$, *** $p < .001$

Table 5: Correlations Among Individual Facets of Religiosity for Individuals with Dementia

	Subjective Appraisal	Frequency of Prayer	Attendance at Religious Services	<i>M</i>	<i>SD</i>
Subjective Appraisal	--			3.96	1.80
Frequency of Prayer	0.62***	--		4.74	2.09
Attendance at Religious Services	0.30**	0.28**	--	2.43	1.76

Note: $N = 103$; * $p < .05$, ** $p < .01$, *** $p < .001$

Paired Sample T-Tests

The second hypothesis posited that the extent of religiosity—measured by subjective appraisal, frequency of prayer, and frequency of attendance at religious services—would not be significantly different on any dimension between caregivers and individuals with dementia. Consistent with this hypothesis, total extent of religiosity (as measured by the mean score of all three religiosity items) was not significantly different between caregivers and individuals with dementia when examined by t-tests ($t(110) = 1.59, p = 0.12$). However, examining each religiosity item independently yielded different findings. Frequency of prayer differed significantly between caregivers and individuals with dementia ($t(109) = 2.20, p < 0.05$), with caregivers on average praying more than individuals with dementia (caregiver: $M = 5.24$, IWD: $M = 4.74$). Subjective appraisal of religiosity also differed significantly

between caregivers and individuals with dementia ($t(107) = 3.60, p < 0.001$), with caregivers endorsing higher ratings on average (caregiver: $M = 4.63$, IWD: $M = 3.98$). Frequency of attendance at religious services did not differ significantly ($t(109) = 1.18, p = 0.24$).

Within the same vein, it was hypothesized that caregiver reports of the individual with dementia's religiosity would not be significantly different from self-reports by the individual with dementia. This hypothesis was partially supported. Subjective reports of how religious/spiritual the caregiver believes the individual with dementia to be were not significantly different from the individuals with dementia's own subjective appraisal ($t(107) = -0.42, p = 0.68$) (caregiver: $M = 3.89$, IWD: $M = 3.96$). However, how important the caregiver believes it is for the individual with dementia to practice religion was significantly different from the individual with dementia own report of how important it is to practice religious beliefs ($t(106) = -4.12, p < 0.001$). Caregiver reports on average underestimated the individual with dementia reports about the importance of religious beliefs (caregiver: $M = 3.48$, IWD: $M = 4.46$).

We then compared African American versus non-African caregivers and African American versus non-African American individuals with dementia. We tested the mean differences among religiosity variables between these groups. African Americans caregivers displayed significantly higher mean scores on items of subjective appraisal ($t(107) = 3.50, p < 0.001$) (AA: $M = 5.09$, non-AA: $M = 4.15$), frequency of prayer ($t(109) = 3.62, p < 0.001$) (AA: $M = 5.78$, non-AA: $M = 4.60$), attendance at religious services ($t(109) = 3.09, p < 0.001$) (AA: $M = 3.17$, non-AA: $M = 2.11$), and the total religiosity scale ($t(109) = 4.41, p < 0.001$) (AA: $M = 4.67$, non-AA: $M = 3.62$) when compared to non-African American caregivers. African American individuals with dementia demonstrated significantly higher mean scores on frequency of prayer ($t(107) = 3.37, p < 0.001$) (AA: $M = 5.44$, non-AA: $M = 4.18$) and total extent of religiosity ($t(107) = 2.01, p < 0.05$) (AA: $M = 4.03$, non-AA: $M = 3.49$) when compared to non-African Americans.

Multiple Linear Regressions

Multiple regressions were used to examine predictors of self-reported quality of life for caregivers and individuals with dementia. For caregivers (Table 6), Models 2 and 3 are significant at the $p < 0.05$ level (Model 2: $R^2 = 0.27$, $F = 4.15$; Model 3: $R^2 = 0.30$, $F = 4.09$). After accounting for sociodemographic variables and care-related stressors, we find that the relationship between the caregiver and the individual with dementia significantly predicts caregiver quality of life ($\beta = 0.25$, $p < 0.05$), with spouses reporting higher quality of life. Care-related stressors related to behavior problems ($\beta = -0.25$, $p < 0.05$), loss of self ($\beta = -0.23$, $p < 0.05$), and role overload ($\beta = -0.27$, $p < 0.05$) exhibit negative associations with quality of life. Caregivers reporting higher levels of behavior problems, loss of self, and role overload also report lower levels of quality of life.

Table 6: Hierarchical Multiple Regression Analyses Predicting Quality of Life of Caregivers

Variables	Model 1			Model 2			Model 3		
	B	SE _B	β	B	SE _B	β	B	SE _B	β
<i>Step 1</i>									
Race	-0.01	0.13	-0.01	-0.06	0.12	-0.07	-0.12	0.12	-0.13
Relation	0.20	0.12	0.21	0.21†	0.11	0.23	0.23*	0.11	0.25
Education	-0.01	0.05	-0.04	-0.01	0.04	-0.04	0.01	0.04	0.03
<i>Step 2</i>									
Behavior Problems				-0.01*	0.00	-0.22	-0.01*	0.00	-0.25
Loss of Self				-0.14†	0.07	-0.21	-0.15*	0.07	-0.23
Overload				-0.17**	0.06	-0.30	-0.16*	0.06	-0.27
<i>Step 3</i>									
Total Religiosity							0.06†	0.04	0.21
R^2	0.05			0.27			0.30		
ΔR^2	--			0.22			0.03		
F	1.14			4.15**			4.09**		

Note: $N = 75$; † $p < .10$, * $p < .05$, ** $p < .01$

For individuals with dementia (Table 7), Models 1 and 3 were significant at the $p < 0.01$ level, and Model 2 was significant at the $p < 0.05$ level (Model 1: $R^2 = 0.12$, $F = 4.68$; Model 2: $R^2 = 0.12$, $F = 3.48$; Model 3: $R^2 = 0.17$, $F = 3.84$). After accounting for sociodemographic variables and level of cognitive impairment, we find that education is significantly associated with individual with dementia quality of life ($\beta = 0.25$, $p < 0.05$), with higher levels of education associated with higher quality of life. We also find that total religiosity is significantly associated with quality of life ($\beta = 0.21$, $p < 0.05$), with higher levels of religiosity associated with higher quality of life.

Table 7: Hierarchical Multiple Regression Analyses Predicting Quality of Life of Individuals with Dementia

Variables	Model 1			Model 2			Model 3		
	<i>B</i>	<i>SE_B</i>	β	<i>B</i>	<i>SE_B</i>	β	<i>B</i>	<i>SE_B</i>	β
<i>Step 1</i>									
Race	-0.11	0.09	-0.12	-0.11	0.09	-0.12	-0.12	0.09	-0.15
Relation	0.08	0.10	0.09	0.08	0.10	0.09	0.10	0.10	0.12
Education	0.06*	0.03	0.22	0.06†	0.03	0.22	0.07*	0.03	0.25
<i>Step 2</i>									
MMSE				0.00	0.01	0.01	0.00	0.01	-0.01
<i>Step 3</i>									
Total Religiosity							0.06*	0.03	0.21
R^2		0.12			0.12			0.17	
ΔR^2		--			0.00			0.04	
<i>F</i>		4.68**			3.48*			3.84**	

Note: $N = 103$; † $p < .10$, * $p < .05$, ** $p < .01$

Multi-Level Models

Given the findings from the multiple linear regressions that total religiosity for individuals with dementia is associated with quality of life, we then moved forward using a two-intercept multi-level model to examine the actor-partner effects between caregivers and individuals with dementia for

predicting individual with dementia quality of life—as self-reported by the individual with dementia and by the caregiver perception. The between dyad variance versus within dyad variance can be measured by the ICC (0.3011). We find that 30.1% of our variance in the outcome variable can be attributed to similarities within dyads, while 70.00% of the variance in reports of perceptions of individual with dementia quality of life can be attributed to differences within dyads. Finding this distribution of variance in reports of perceptions of individual with dementia quality of life, we added controls of between-dyad level characteristics to control for significant effects before moving on to the primary predictors of interest. We find that caregivers and individuals with dementia report significantly different levels of individual with dementia quality of life—individuals with dementia report higher levels of quality of life than caregivers report about the individual with dementia, and these reports are significantly different than zero. Caregiver stress and caregiver feelings of loss of self are related to reports of an individual with dementia’s quality of life. Dyads with more stress (as reported by the caregiver) report lower levels of individual with dementia quality of life. For both caregivers and individuals with dementia, for every one unit increase in stress there is a 0.01 decrease in quality of life. Caregivers who have greater feelings of loss of self at Time 3 are members of dyads with higher reports of individual with dementia quality of life at Time 1. For both caregivers and individuals with dementia, for every one unit increase in loss at Time 3, there is a 0.15 increase in quality of life at Time 1.

In examining actor effects in Model 3 (effects of own perceptions on own report of individual with dementia quality of life) (Table 8), we see that own reports of total religiosity are actually not predictive of own reports of individual with dementia’s quality of life, in contrast to findings from the multiple linear regressions. Rather, how important the caregiver reports religious practice to be to the individual with dementia is significantly predictive of caregiver reports of individual with dementia’s quality of life. For each one-unit increase in importance, caregivers also report a 0.17 increase in individual with dementia quality of life. For individuals with dementia, we also see a significant relationship of importance of religious practice for them on their own self-reports on quality of life. For each one-unit increase in their reports of the importance of religious practice, there is a 0.18 increase in

their self-reports of quality of life. Then to examine if caregiver reports of their own religiosity and their perception of importance to the individual with dementia affect reports of quality of life by the individual with dementia *and* to examine if individual with dementia reports of their own religiosity and their own reports of importance affect reports of quality of life by the caregiver, we added in partner effects. In so doing, we find that the previous actor effects are no longer significant. We see a partner effect such that caregivers reports of how important they believe religious practice to be to the individual with dementia predicts the individual with dementia's self-reports of quality of life.

Table 8: The influence of religiosity and individual and dyadic-based characteristics on caregivers' and IWDs' perceptions of IWDs' quality of life

	MODEL 1		MODEL 2		MODEL 3		MODEL 4	
	<i>B</i>	<i>SE</i>	<i>B</i>	<i>SE</i>	<i>B</i>	<i>SE</i>	<i>B</i>	<i>SE</i>
Fixed effect								
Intercept for CG	2.37 ^{***}	0.04	2.33 ^{***}	0.05	2.32 ^{***}	0.05	2.31 ^{***}	0.04
Intercept for IWD	2.66 ^{***}	0.04	2.62 ^{***}	0.05	2.61 ^{***}	0.05	2.60 ^{***}	0.05
Actor effects								
Total_Religiosity for CG	--	--	--	--	-0.06	0.04	-0.06 [†]	0.04
Total_Religiosity for IWD	--	--	--	--	-0.04	0.04	-0.009	0.05
Importance of Religiosity to the IWD reported by the CG	--	--	--	--	0.17 [*]	0.06	0.07	0.07
Importance of Religiosity to the IWD reported by the IWD	--	--	--	--	0.18 [*]	0.08	0.14 [†]	0.08
Partner effects								
Total_Religiosity for CG	--	--	--	--	--	--	0.03	0.04
Total_Religiosity for IWD	--	--	--	--	--	--	-0.04	0.04
Importance of Religiosity to the IWD reported by the CG	--	--	--	--	--	--	0.18 [*]	0.08
Importance of Religiosity to the IWD reported by the IWD	--	--	--	--	--	--	0.01	0.07
Control Variables								
Caregiver Stress*CG	--	--	-0.01 ^{***}	0.003	-0.01 ^{***}	0.003	-0.01 ^{***}	0.003
Caregiver Stress*IWD	--	--	-0.01	0.003	-0.009 ^{**}	0.003	-0.008 [*]	0.003
Caregiver Loss of Self (T3)*CG	--	--	0.15 [*]	0.07	0.17 [*]	0.07	0.18	0.07
Caregiver Loss of Self (T3)*IWD	--	--	0.16 [*]	0.07	0.19 ^{**}	0.07	0.17 [*]	0.07
Random effect (CSH)								
Var(1)	0.21 ^{***}	0.03	0.16 ^{***}	0.03	0.16 ^{***}	0.03	0.14 ^{***}	0.02
Var(2)	0.19 ^{***}	0.03	0.16 ^{***}	0.03	0.14 ^{***}	0.02	0.14 ^{***}	0.03
Residuals	0.30 ^{***}	0.09	0.18	0.11	0.008	0.13	0.01	0.13
-2 Log Likelihood	266.1		178.7		180.4		178.9	
AIC	272.1		184.7		186.4		184.9	

Note. Dyad $N = 111$. † $p < .10$. * $p < .05$. ** $p < .01$. *** $p < .001$. Model 2 also tested the effects of Relation (Spouse = 1), Race (African American = 1), IWD's T1 MMSE, Caregiver Overload (T3), and Education (reported by each individual) but all were non-significant and were dropped from further model building.

^aTotal Religiosity represents a compilation of three items for each person (VAR1, VAR2, and VAR3) reflecting one's total subjective practice/importance of religion.

Post-Hoc Analyses

The two-intercept model estimated coefficients and the p-values for each the caregiver and individual with dementia effects separately. Thus, this model provided all 4 actor and partner effects per one predictor (e.g., actor effect for caregivers, partner effect for caregivers, actor effect for individual with dementia, and partner effect for individual with dementia). However, this analysis does not allow us to say how much the coefficients differ between caregivers and individuals with dementia or how statistically meaningful the differences in the coefficients are. As such, we ran a post-hoc analysis using a one-intercept model to determine if actor and partner effects differ between caregivers and individuals with dementia by looking at the significance of interaction terms. In examining actor effects, we find no significant interactions (i.e., differences between caregivers and individuals with dementia) across the two key religiosity variables. However, one's own perception of how important religiosity is to the individual with dementia is predictive of one's own perceptions of individual with dementia quality of life. After adding in partner effects, there are no significant interactions (i.e., differences between caregivers and individuals with dementia) across the two key religiosity variables. With the partner effects in the equation, the individual with dementia's own report of how important religiosity is predicts his/her self-reported quality of life. Additionally, the caregiver's perception of how important religiosity is to the individual with dementia is predictive of the caregiver's perception of individual with dementia quality of life.

We ran an additional post-hoc analysis to examine the effects of both religiosity variables independently. This model ran the values and preferences item of importance of practice separately and from the total religiosity variable separately. When we run the effects independently in the model instead of both in the model together, the only difference is that there is now a significant effect of partner's total religiosity on caregiver reports of individual with

dementia quality of life in addition to the effect of importance. Thus, when the individual with dementia reports higher levels of total religiosity or importance of religiosity, the caregiver reports higher quality of life for the individual with dementia. Our primary findings indicate that when we account for the effects of total religiosity and importance of the individual with dementia practice in the model together, the individual with dementia's reports of how important religious practice is to him/her is significantly related to caregiver reports of the individual with dementia's quality of life above and beyond the effects of total religiosity.

Chapter 4

Discussion

Overall, we find that religiosity plays an important role in the lives of individuals with dementia, both independently and in the context of the caregiver and individual with dementia dyad. Utilizing several measures of religiosity, we found that individuals with dementia who report higher total religiosity also exhibit higher levels of quality of life. These findings were not evident in the caregiver population. However, caregivers play an active role in the context of religiosity, as it is their perceptions of individual with dementia's religiosity that impact outcomes for the individual with dementia. This study is one of few to address individuals with dementia in the context of religiosity, as it is sometimes assumed that they simply cannot be reached spiritually (Snyder, 2003). Moreover, religiosity has not been examined in the context of the dyad. These findings emphasize the importance of establishing a sense of understanding between the caregiver and the individual with dementia regarding religiosity, as we see that even perceptions of beliefs play a strong role.

We supported previous findings that caregivers report high frequency of prayer and subjective religiosity. However, we did find that attendance at church services was significantly correlated with other aspects of practice, which has not been supported in other populations of caregivers (Herbert et. al., 2007).

We did not see unique effects of religiosity for the caregiver population. Within this sample, feelings of stress, loss of self, and overload are actually more predictive of quality of life. Though caregivers may utilize religiosity as a coping mechanism, it does not appear that this mechanism uniquely contributes to improving quality of life. In examining the African-American caregiver population, we did find show that African-Americans demonstrate significantly higher levels of religiosity compared to non-African Americans. However, effects of religiosity on

quality of life within this sub-population were not significant. These findings contrast previous research showing that African-Americans may draw more support and positive outcomes from their religiosity as compared to non-African Americans.

Religiosity was associated with higher overall quality of life for individuals with dementia. The finding regarding the effects of religiosity on quality of life for individuals with dementia emphasize the importance of understanding their values. Religion is just another aspect that should be addressed in the effort to provide person-centered care (Doherty, 2006). Caregivers should discuss these issues with individuals with dementia early on in care, given that abilities will change with time. Caregivers can then honor these wishes and aid the individual with dementias when they are no longer able to clearly articulate their specific desires. The level of dependence of the individual with dementia on the caregiver makes it crucial for the caregiver to aid the individual with dementia in their practice. At the same time, it is important to note that we did not have data related to stressors in the lives of the individuals with dementia, as we had for the caregiver. Including such measures would give a more complete picture of the effects of religiosity.

It is interesting to note that although we see effects of religiosity for individuals with dementia, caregivers actually displayed higher frequency of prayer and higher subjective appraisal of their religiosity. As expected, frequency of attendance at religious services did not differ significantly between the two groups, possibly supporting the assumption that individuals with dementia rely on their caregivers to attend services. However, total religiosity, encompassing all three facets of religiosity, did not differ significantly between caregivers and individuals with dementia.

The finding regarding the role of religiosity in the lives of individuals with dementia suggested that examining the effects at the level of the dyad would be beneficial. As discussed, the individual with dementia is highly dependent on the caregiver to practice certain aspects of

religion, such as attending church services. As such, the caregivers' views regarding their own religious practice and their perceptions regarding the individual with dementia's practice are important to examine. We found that caregivers' reports of how religious they believe the individual with dementia to be did not differ from individual with dementia own reports of how religious they are. However, the distinction lies in how important the caregiver actually believes it is for the individual with dementia to practice religion. Caregiver perceptions actually underestimated reports by the individual with dementia, emphasizing the importance of communication. These findings parallel previous reports that caregivers consistently underestimate the values of individuals with dementia (Reamy, Kim, Zarit, & Whitlatch, 2011). If individuals with dementia believe it is of greater importance to practice, they need the caregiver's support to do so.

The multi-level models allowed us to make conclusions at the level of the dyad. In contrast to findings from linear regressions, we do not see effects of total religiosity predicting quality of life for the individual with dementia. Rather, we find that partner effects exist such that caregiver reports of how important they see religious practice to be to the individual with dementia predicts the reports of quality of life by the individual with dementia. It is possible that caregivers view religion as more important because individuals with dementia who have quality of life exhibit certain behaviors or attitudes. The findings are salient in that they demonstrate the power of personal values and beliefs and underscore the importance of communication.

A strength of this study was that we did have a religiosity construct that addresses multiple aspects of religious practice. However, high religiosity could be linked to various behaviors that are related to higher overall well-being (Herbert et al., 2007). We did not have baseline data on health habits or lifestyle practices (refraining from smoking, drinking, etc.) that could play such a role. Thus, religion could be manifesting itself as a proxy for generally healthy behaviors. Given that we utilized a cross-sectional study design, we are also unable to establish

whether higher overall religiosity leads to higher overall quality of life, or if people who have higher quality of life tend to manifest certain religious beliefs. Religion and attendance at religious services may also be less about personal beliefs and more about a desire for social integration and contact (Herbert, 2007). We did not have detailed religiosity scales that address specific questions about whether religion is used to deal with difficult times and stress (Krause, 1998; Schaefer & Gorsuch, 1993), so we were not able to untangle these issues. A measure targeted towards caregivers would be ideal, as it would allow us to specifically understand individual motivation to practicing religion.

Though there are ways in which the study could be improved, the findings make it evident that there is room for further inquiry. Religion has been demonstrated to be of great importance to both the caregivers and individuals with dementia, and it is evident that beliefs of the caregiver have a salient effect on reports by the individual with dementia. Communication and understanding of the individual with dementia's preferences could have marked results in improving quality of life for the individual with dementia.

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ACADEMIC VITA

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Education

Major: Biology (Neuroscience Option)

Minors: Human Development and Family Studies *and* Gerontology

Honors: Biology *and* Human Development and Family Studies

Honors and Awards

President's Freshman Award

Evan Pugh Scholar Award (Senior)

Dean's List

First Place: Behavioral and Social Sciences, 2013 PSU Undergraduate Research Exhibition

Association Memberships/Activities

Schreyer Honors Orientation Global Engagement Team Leader

2012; 2013: Planned and oversaw events for the 3-day freshmen orientation.

Alpha Epsilon Delta National Health Pre-professional Honor Society

2010-2013: Contributed to Social/Public Relations, Blood Cup, THON, and Public Health Fair Committees.

Rotaract Service Club

2010-2013: Volunteered with local organizations, including The Oaks at Pleasant Gap Retirement Home.

Hindu Student Council

2010-2013: Attended religious and cultural events.

Global Medical Brigades

2011-2012: Traveled to Panama in March 2012 on a Medical/Dental brigade. Recipient of Schreyer Honors College travel grant.

Schreyer Honors College Student Council

2010-2013: Contributed to Formal, Merchandise, and Date Auction committees. Scholar Tour Liaison. Relay for Life Team.

University Libraries Undergraduate Student Advisory Group

2011-2014: Served as a student Representative.

Work Experience

Department of Human Development and Family Studies Research Assistant

Dr. Steven Zarit, Ph.D

Spring 2012-present: Research focusing on care giving for the elderly, health and functioning of elderly, mental health problems in elderly. Worked on Daily Stress and Health (DASH) study and trained in using SPSS

Penn State Undergraduate Mathematics Department Proctor

September 2012-present: Oversee 200-250 person exams in large lecture halls. Administer exams for the Office of Disability Services for eligible students.

Summer Intern at Weis Center for Research (Geisinger Medical System)

Dr. Wannian Yang, Ph.D

May-August 2012: Learned cell culture techniques, maintained MB231 and MCF7 breast cancer cell lines, conducted Western blot and protein microarrays. Completed a project entitled "Determination of Geranylgeranylation-Associated Cellular Signaling." Recipient of Schreyer Honors College Internship Grant.

Justice Sales Associate

November 2011-January 2012: Maintained an organized store and completed customers' purchases.

Department of Biobehavioral Health Research Assistant

Dr. William Gerin, Ph.D (The Mind-Body Cardiovascular Psychophysiology Laboratory)

Fall 2011; Trained to operate Nexfin to record heart rate and blood pressure and conducted clinical trials independently

Bon-Ton Sales Associate

November 2009-November 2010: Assisted customers while they were shopping and checking out.

Community Service

Susquehanna Health

October 2005-May 2013: Muncy Valley Skilled Nursing Unit: Visited individually with residents and aided in group activities; Muncy Valley Emergency Room: Observed procedures and filed patient charts; Divine Providence Cancer Treatment: Aided in Chemotherapy room to clean chairs, stock carts, and provide patients with any requested items. Served as lab escort to transport patients to get blood work.

Camp Victory Camp Counselor, Millville, PA

2011-2012: Camp facility designed for children with chronic health problems or disabilities. Camp Emerge (Autism/Family Camp); Camp Cranium (Traumatic Brain Injuries); PA Vent Camp (Ventilator dependent children); Camp JRA (Juvenile arthritis and rheumatic illness); Camp Spifida (Spina Bifida) .

Professional Presentations

The Gerontological Society of America Annual Scientific Meeting

November 2013: Poster entitled "The Influence of Religiosity on Quality of Life: Individuals with Dementia and their Family Caregivers"