2013

Spirituality, Faith, and Mild Alzheimer's Disease

Jocelyn Shealy McGee

Dennis R. Myers

Holly Carlson

Angela E. Pool-Funai

Paul A. Barclay

Spirituality, faith, and early stage Alzheimer's disease

Article *in* Journal for the Scientific Study of Religion · January 2013

CITATIONS
2

READS
513

5 authors, including:

Jocelyn Shealy Mcgee
Baylor University
62 PUBLICATIONS **390** CITATIONS
SEE PROFILE

Paul Barclay
University of Central Florida
15 PUBLICATIONS **31** CITATIONS
SEE PROFILE

Angela Pool-Funai
Southern Utah University
4 PUBLICATIONS **4** CITATIONS
SEE PROFILE

Research in the Social Scientific Study of Religion

Volume 24

Edited by

Ralph L. Piedmont
Loyola University Maryland
and
Andrew Village
York St. John University, UK

BRILL

LEIDEN • BOSTON
2013

 ISBN 978-90-04-25205-9

CONTENTS

 ISBN 978-90-04-25205-9

 ISBN 978-90-04-25205-9

SPIRITUALITY, FAITH, AND MILD ALZHEIMER'S DISEASE

Jocelyn Shealy McGee, Dennis R. Myers, Holly Carlson, Angela Pool Funai, and Paul A. Barclay*

Abstract

There is some evidence for a positive association between spirituality, cognitive, and behavioral functioning in people with Alzheimer's disease (AD). However, to our knowledge there is no published data to date that provides an explanatory model for these findings. Twenty-eight individuals with mild AD received in-depth interviews and measures of cognitive, behavioral, emotional, and spiritual functioning to gain insight into this question in this mixed methods study. Findings revealed that people with mild AD can actively engage in meaningful discussion about how spirituality influences their experience of living with AD; that they remain deeply devoted to a relationship with the transcendent (i.e., God, higher power, spirit) and their spiritual communities; that they value and benefit from the sacred aspects of their day-to-day lives; and that their core spiritual values, beliefs, and practices can be activated to help them adapt to the uncertainty of living with AD. Additionally, persons with AD who are experiencing spiritual struggle tend to experience a greater degree of anxiety, depression, and behavioral changes as compared to those

* *Authors Note*: Jocelyn Shealy McGee, Alzheimer's Disease and Memory Disorders Center, Department of Neurology, Baylor College of Medicine; Dennis R. Myers, School of Social Work, Baylor University; Holly Carlson, Amazing Place Memory Care & Wellness Center, Houston, TX, USA; Angela Pool Funai, School of Social Work, Baylor University; Paul A. Barclay, University of Texas.

This work was supported in part by the Baylor College of Medicine Alzheimer's Disease and Memory Disorders Center, Department of Neurology; Baylor University; and the Amazing Place Memory Care and Wellness Center. Funding was provided, in part, by the Danny and Lenn Prince Endowed Fund for Residential Care at Baylor University. The following organizations were especially helpful in spreading the word about the study: Interfaith Carepartners, Sid Gerber and Associates, Alzheimer's Association, North Texas Chapter, and the Buckner Retirement Community.

Special thanks to the following individuals who assisted in various ways in the study including Alyssa Cain, Ashley Kuhn, Amy Lattimore, Alex Scheibner, and Angela Traylor. Additionally, we would like to express gratitude to Dr. Ken Pargament for his input as we grappled with the initial design for this study as well as for his ongoing encouragement. Likewise, the first author greatly appreciates Dr. Dennis Myers for inspiring me to become a gerontologist back in 1991 and for the opportunity to collaborate with him on this project. And most importantly, thank you to the incredible people who participated in this study and shared their journeys. Their input was invaluable and their lives are an inspiration to us.

The views expressed reflect those of the authors and not necessarily those of Baylor College of Medicine, the Universities of Texas, Baylor University, or the Amazing Place Memory Care and Wellness Center.

Correspondence about this paper should be addressed to Jocelyn Shealy McGee, Department of Neurology, Baylor College of Medicine, 1977 Butler Blvd., Ste. E5.101, Houston, TX 77030, Ph: 713-798-7791, Fax: 713-798-7434. Email: jmcgee@bcm.edu

Research in the Social Scientific Study of Religion, Volume 24

 ISBN 978-90-04-25205-9

who do not, suggesting that spiritual struggle is a risk factor for poorer outcomes in this population. Implications for future research, clinical practice, and community care are provided including how researchers and clinicians can effectively adapt traditional measures of spirituality for use with this population; the importance of integrating spirituality into the assessment and treatment of people with AD; and the role spiritual communities can play in helping or hindering people with AD as they adapt to this disease.

Keywords: religion, spirituality, coping, Alzheimer's disease

> When the sands are shifting in other parts of your life, you know why God is the rock.
>
> —Person with mild Alzheimer's disease

Dementia is a neurocognitive syndrome characterized by global cognitive decline across several domains, most notably memory, but also attention/concentration, language, visuospatial/constructional skills, and executive functioning which leads to subsequent difficulties carrying out one's day to day tasks. Dementia is an umbrella term for several diseases stemming from diverse etiologies including progressive neurodegenerative disease such as Alzheimer's disease (AD), Frontotemporal dementia (FTD), dementia with Lewy bodies, and dementia with parkinsonism, among others; diseases which tend to be more variable in their course and progression such as vascular dementia, alcohol-induced persisting dementia, and dementia associated with traumatic brain injury (TBI), among others; and diseases with potentially treatable etiologies such as endocrine or metabolic disorders, infectious disease, vitamin deficiencies, among others (McGee & Bratkovich, 2011). Autopsy studies (Holmes, Cairns, Lantos, & Mann, 1999; Lim et al., 1999), clinical series (Thai, Grundman, & Klauber, 1988), and population-based surveys (Fillenbaum et al., 1998) suggest that AD is the most frequent etiology of dementia in North America and Europe.

Dementia presents a significant global public health challenge. There are approximately 36 million people currently living with dementia which is projected to rise to 66 million by 2030 and to 115 million by 2050 (Prince, Bryce, & Ferri, 2011). In the USA, one in eight people over the age of 65 is affected (Hebert, Scherr, Bienias, Bennett, & Evans, 2003) which translates into 5.4 million, a number which is projected to rise to 13.6 million by 2050 (Alzheimer's Association, 2011). The global fiscal cost of dementia is about $604 billion (USD) which is greater than 1% of the global Gross Domestic Product (Wimo & Prince, 2010). If dementia were a nation, it would represent the world's largest economy according to the World Alzheimer's Report (Wimo & Prince, 2010). In addition to the financial costs of

 ISBN 978-90-04-25205-9

dementia, the emotional and social costs of dementia can be devastating to individuals, families, friends, and communities.

Over the last decade, a generally positive connection between spirituality and health has been demonstrated in a range of clinical populations. Examples include faster time to recovery after the onset of illness, increased longevity, decreased mortality, increased coping abilities, and relatively better quality of life in the midst of illness (Levine & Targ, 2002; Luskin, 2000; McCullough, Hoyt, Larson, Koenig, & Thoresen, 2000; Mueller, Plevak, & Rummans, 2001; Seeman, Dubin, & Seeman, 2003; Sloan & Bagiella, 2002; and Sloan, Bagiella, & Powell, 1999). Despite these generally positive findings, there is a paucity of research examining the connections between spirituality and health in people with AD and other forms of dementia, although anecdotal reports suggest that cognitively affected individuals can respond positively to faith-based activities such as singing familiar hymns or participating in religious rituals (Shamy, 2003). For example, Sachs (1998) discussed his experience with Jimmie, a Navy Veteran diagnosed with Korsakov's dementia, a dementia that had rendered him unable to recall the past, build new memories, or form emotional connections even though he could engage in communion at Mass. Another example is one of the authors' (JSM) experiences working at a church-based adult day health center in which Dovie, a woman with advanced AD, became significantly agitated and was calmed when she was engaged with a hymn from her religious heritage. Remarkably, she had not communicated verbally for almost 2 years but was able to relax and sing the familiar hymn with the author (McGee, 2012).

A few intriguing studies have examined the relationship between religious attendance and normal cognitive aging (Hill, 2006). An analysis of data from the New Haven Established Populations for Epidemiological Studies of the Elderly survey (n = 2,812) revealed that attendance at worship services was predictive of cognitive functioning over the span of 3 years on a brief measure of cognitive status controlling for a number of sociodemographic and health related variables (Van Ness & Kasl, 2003). Specifically, those who attended religious services less than once per week had lower scores on the cognitive measure as compared to those who attended religious services at least once weekly suggesting poorer cognitive functioning over time in those with less frequent worship attendance. In another study, religious attendance was associated with a slower rate of decline on cognitive scores over 8 years in a sample of people of Mexican-origin (n = 3,050) aged 65 and over controlling for key socio-demographic and health related factors (Hill, Burdette, Angel, & Angel, 2006).

 ISBN 978-90-04-25205-9

Findings from a study on people with AD (n = 68) suggested that higher levels of religiosity and private religious practices were associated with slower rate of decline on a brief cognitive measure over the span of 3 years (Kaufman, Anaki, Binns, & Freedman, 2007). Another study found a slower rate of progression over 12 months on a cognitive screening measure in persons with AD who had a high degree of religious participation at baseline as compared to persons with AD with a low degree of religious participation at baseline (Coin et al., 2010). Also, fewer behavioral and psychological symptoms associated with dementia (BPSD) were reported by family members of individuals in the high religious participation group as compared to those in the low religious participation group. At baseline there were no significant differences between these groups on measures of cognitive, functional, and behavioral measures accounting for important socio-demographic variables.

In the current study, we sought to build upon previous research by providing an explanatory model for how spirituality impacts the lives of people with AD. We present qualitative data from interviews of people with AD on the following aspects of spirituality: (a) values and beliefs as they relate to living with AD; (b) the role of the sacred in the lives of people with AD; (c) private and corporate (within a formal congregational setting) spiritual practices; and (d) how spirituality aids in coping with AD. Additionally, using quantitative measures, we hypothesized that individuals who utilize negative religious coping to a greater degree than positive religious coping would report greater symptoms of anxiety, depression, and behavioral changes.

Methods

Participants

Inclusion criteria were: (a) age 55 or older; (b) diagnosis of AD; (c) Clinical Dementia Rating (CDR) score of 1 (mild dementia); (d) fluent in English; and (e) ability to complete a structured interview and other measures with assistance from a trained examiner. Exclusion criteria were: (a) severe psychiatric problems such as untreated schizophrenia or bipolar disorder; (b) severe aphasia; (c) severe hearing problems; (d) not fluent in English; and/or (e) unwilling or unable to complete a structured interview and other measures with assistance from a trained examiner.

Twenty-eight individuals with mild AD participated in the study (see Table 1 for demographic characteristics).

 ISBN 978-90-04-25205-9

Table 1. *Demographic Characteristics of Sample*

	N	%
Sex		
Male	12	42.9
Female	16	57.1
Age, years (*M*, *SD*)	77.88	(9.88)
Education (*N* = 23)		
High school graduate	2	7.7
GED	4	15.4
Some college	4	15.4
Bachelor's degree	6	23.1
Master's degree	5	19.2
Doctoral degree	2	7.7
Ethnicity		
Hispanic or Latino	2	7.1
Not Hispanic or Latino	26	92.9
Race		
Asian-American	1	3.6
Black or African-American	1	3.6
Caucasian	26	92.9
Marital Status		
Married	16	57.1
Widowed	9	32.1
Divorced/Separated	2	7.1
Single, Never Married	1	3.6
Religious Affiliation (*n* = 24)		
Catholic	2	8.3
Protestant	20	83.3
None	1	4.2
Other	1	4.2

Note: Number (*N*) and percent (%) of participants with a given characteristic reported unless specified otherwise; Mean (*M*); Standard Deviation (*SD*); Graduate Equivalency Diploma (*GED*)

There were more women (57.1%) than men with a mean age of 78.26 (*SD* = 9.88) for the entire sample. Caucasian-Americans were overrepresented (*n* = 26; 92.9%) with only one African-American and one Asian-American participant. The sample was highly educated with the majority of participants having at least some college. Most participants were married (57.1%) or widowed (32.1%). The majority of participants self-identified as Christian (Catholic, 8.3%; Protestant, 83.3%). Among Protestants, several religious affiliations were represented including Anglican/Episcopal, Baptist, Lutheran, Methodist, non-denominational, and Presbyterian.

 ISBN 978-90-04-25205-9

Ethical Considerations

The study was approved by the Baylor College of Medicine and Baylor University Institutional Review Boards. Written informed consent was obtained from all participants during a face-to-face appointment. Participants signed their own consent forms unless there was a legal guardian or power of attorney (POA) in which case the guardian or POA also signed the consent form. All participants were able to comprehend the purpose of the study and give consent. In participants who evidenced lack of insight into having a diagnosis of AD, we used the term *memory or thinking changes* instead of dementia or AD during the interview process.

Procedure

Participants were recruited primarily from the Alzheimer's Disease and Memory Disorders Center (ADMDC), Department of Neurology, Baylor College of Medicine and the Amazing Place Memory Care and Wellness Center during their regularly scheduled clinic or program appointments. Several residents of the Buckner Retirement Community in San Angelo, TX participated in the study as well as one person affiliated with the Alzheimer's Association of North Texas. Several community agencies who serve people with memory disorders distributed announcements about the study. If an individual expressed interest in the study after receiving a study flyer, permission was requested to allow the researchers to contact them and a family member by telephone in order to provide additional information about the study. Upon assent, researchers contacted potential participants and their family member, provided them with detailed information about the study, screened them for eligibility, and scheduled an in-person appointment with them within 1–2 weeks for the purposes of informed consent.

Data Collection

After giving written consent, participants received a structured interview and completed quantitative measures (described below). Interviews were conducted in a private office space primarily by one researcher (HC), were recorded, and took an average of 45 minutes to complete after which participants received a 15-minute break. After the break, participants received a set of verbally administered measures (described below). These measures, which were adapted from existing measures, took an average of 30 minutes to complete. All interviews were transcribed by a trained transcriptionist and later audit checked by a second trained transcriptionist.

 ISBN 978-90-04-25205-9

Interview

The Dimensions of Living with Dementia (DLD) interview was developed by McGee and Carlson (2011) with input from an expert panel comprised of four clinicians specializing in dementia care (one neuropsychologist, two psychologists, and one social worker) and two spirituality and health researchers. The interview has three sections: (a) Impact of Living with Dementia; (b) Spiritual and Religious Dimensions of Living with Dementia; and (c) Positive Psychological Dimensions of Living with Dementia which addresses constructs such as hope, forgiveness, resilience, and other factors. See Appendix A for the Spiritual and Religious Dimensions of Living with Dementia section of the DLD Interview. Contact the first author for a copy of the DLD.

Measures

In addition to the DLD interview, participants received measures of cognitive, emotional, behavioral, and spiritual functioning. These measures were adapted, as needed, to accommodate for a variety of cognitive difficulties that people with early-stage Alzheimer's disease may experience.

Cognitive, emotional, and behavioral functioning

The Mini Mental Status Examination (MMSE; Folstein, Folstein, & McHugh, 1975) was utilized to assess cognitive functioning. The MMSE, which is a brief cognitive screening measure, is one of the most commonly employed measures of cognitive functioning in the medical field. Scores range from 0 to 30 with higher scores suggesting better cognitive functioning. The overall score is calculated by adding up performance on tasks assessing orientation, working memory, immediate and delayed recall, and visual-spatial skills, among others. People in the mild stages of AD typically score between 20 and 25 points on the MMSE. However, highly educated individuals (as in this sample) in the earliest stages of AD may have higher scores on this measure. This measure was used in its original format.

The Geriatric Anxiety Inventory (GAI; Pachana et al., 2006) was designed to assess severity of anxiety symptoms in older adults. Participants indicate their agreement (1 = *Agree*; 0 = *Disagree*) with 20 statements, such as "I often feel nervous." The greater the number of items endorsed, the more likely the individual is to have an anxiety disorder. Psychometric properties of the measure are adequate for use in a normal older adult population and in older individuals receiving psychiatric treatment (Pachana et al., 2006). The content of the GAI was not modified in this study. However,

 ISBN 978-90-04-25205-9

it was administered by a trained examiner using a stimulus book rather than in a self-report format.

The Geriatric Depression Scale-15 Item (GDS-15; Yesavage et al., 1983) is a 15-item self-report measure that assesses for symptoms of depression. The more items endorsed, the more likely the individual is to have clinical depression. This measure has demonstrated good psychometric properties among patients in primary care settings (Evans & Katona, 1993), residents of nursing homes (McGivney, Mulvihill, & Taylor, 1994), and in older adults receiving outpatient mental health care (Burke, Nitcher, Roccaforte, & Wengel, 1992). The content of the GDS was not modified in this study. However, it was administered by a trained examiner using a stimulus book rather than in a self-report format.

The Neuropsychiatric Inventory Questionnaire (NPI) is a self-report measure that was developed to assess psychopathology in people with dementia (Cummings et al., 1994). It evaluates 12 common neuropsychiatric symptoms: delusions, hallucinations, agitation, dysphoria, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behavior, night-time behavior disturbances, and appetite and eating abnormalities. The severity and frequency of each symptom is rated by an informant who frequently interacts with the person who has dementia. Additionally, the degree of distress experienced by the informant is rated for each symptom. Content validity, concurrent validity, inter-rater reliability, and test-retest reliability of the NPI are well established (Cummings et al., 1994). This measure was used in its original format.

Spiritual functioning

To date, there are no known measures of spiritual functioning developed for use with people with dementia or other populations who have cognitive limitations. Therefore, we adapted existing measures for use with this population with the goal of maximizing comprehension and tapping into cognitive strengths. Prior to determining what modifications were needed, we selected established measures with good psychometric properties in older adults and/or other medical populations (see below for information on each measure).

We gave these measures in their original format to three people with mild AD to test whether or not they could complete the measures on their own and to receive feedback on the measures from their perspective. These individuals reported that the wording of some questions was difficult to understand, especially when questions were asked using double negatives, and that they were overwhelmed by the number of choices

 ISBN 978-90-04-25205-9

on the Likert scales which ranged from 3 to 9. Two participants did not answer all of the questions; when queried, they indicated that they were distracted by the number of items on the page. Based on these findings, we made several adaptations to the measures including using a stimulus book for administration (see Appendix B for specific adaptations).

The Brief RCOPE (Pargament, Smith, Koenig, & Perez, 1998) is a 14-item measure that assesses the degree to which an individual uses positive and/or negative religious coping strategies to deal with life stressors using a 4-point Likert scale. The original Brief RCOPE is composed of two subscales with seven items each. An example of a positive coping strategy is "Looked for a stronger connection with God." An example of a negative coping strategy is "felt punished by God for my lack of devotion." The Brief RCOPE has been used with a variety of populations including adults living with physical and mental illnesses (Pargament et al., 1998). Both subscales have demonstrated good reliability in an older adult sample (Bush et al., 2012).

The Brief RCOPE was adapted for use with people with AD by reducing the number of points on the Likert scale to 3 (Brief RCOPE-AD). The positive religious coping subscale demonstrated good internal consistency with a Cronbach's alpha coefficient of .86 for the adapted scale. The negative religious coping subscale demonstrated acceptable internal consistency with a Cronbach's alpha coefficient of .71 for the adapted scale.

The Religious Problem Solving Scale-Short Version (RPSS; Pargament et al., 1988) is an 18-item self-report measure that assesses the degree to which three religious problem-solving strategies are utilized: (a) Collaborative; (b) Deferring; and (c) Self-Directed. An example of a collaborative religious problem solving statement is, "When considering a difficult situation, God and I work together to think of possible solutions." An example of a deferring religious problem solving statement is, "When a situation makes me feel anxious, I wait for God to take those feelings away." An example of a self-directed religious problem solving statement is, "When deciding on a solution, I make a choice independent of God's input."

In the original RPSS, each item is rated on a 5-point Likert scale (1 = *never*; 5 = *always*). The RPSS has previously demonstrated good test-retest reliability (Fox, Blanton, & Morris, 1998) and internal consistency in an older adult sample (Bush et al., 2012). For the adapted measure (RPSS-AD), we reduced the Likert scale to 3-points and simplified the wording. Cronbach's alpha for the RPSS-AD was .91, .88, and .86 respectively, suggesting strong internal consistency for each subscale.

 ISBN 978-90-04-25205-9

The Santa Clara Strength of Religious Faith Questionnaire (Santa Clara; Plante & Boccaccini, 1997) is a 10-item self-report instrument that measures the general role of faith in an individual's life using a 4-point Likert scale (1 = *strongly disagree*; 4 = *strongly agree*). An example of an item from the Santa Clara is, "My faith is an important part of who I am as a person." The Santa Clara has been used with college students (Freiheit, Sonstegard, Schmitt, & Vye, 2006; Sherman et al., 2001), healthy women (Plante, Vallaeys, Sherman, & Wallston, 2002), and individuals being treated for cancer (Sherman et al., 2001) with good reliability and construct validity. For the adapted Santa Clara (Santa Clara-AD), the Likert scale was reduced to 3-points. Cronbach's alpha was .93, suggesting excellent internal consistency.

The Brief Multidimensional Measure of Religiousness and Spirituality (BMMRS) was developed by the Fetzer Institute and the National Institute on Aging working group (1999) to measure different aspects of religiousness and spirituality. This measure has been widely utilized with a range of populations including older adults with chronic health related conditions (Allen, Hilgeman, Ege, Shuster, & Burgio, 2008). Nearly all domains on the BMMRS have demonstrated adequate convergent and discriminant validity and good-to-excellent reliability in previous studies (Bush et al., 2012; Idler et al., 2003).

In the current study, four subscales from the BMMRS were utilized: Daily Spiritual Experiences (DSE), Values and Beliefs (VB), Private Religious Practices (PRP), and Religious Support (RS). The DSE subscale has six items that assess how often participants feel connected to the sacred. An example from this subscale is "I feel God's presence." The VB subscale has four items that assess religious values and beliefs such as "The events of my life unfold according to a divine plan." The PRP subscale has five items that assess frequency of individual religious and spiritual practices such as, "Within your religious tradition, how often do you meditate?" The RS subscale has four items that assess the degree to which individuals believe they have support from their faith community such as "How often do the people in your congregation make too many demands on you?" For all subscales, the response format was adapted from the original to use a 3-point Likert scale.

Analysis

A mixed methods design was utilized in this study, combining qualitative and quantitative research methodologies, to obtain a more comprehensive

 ISBN 978-90-04-25205-9

understanding of the role of spirituality in the lives of people with mild AD. Three researchers independently read and coded all interviews. The team selected ATLAS.ti, version 6 (Muhr, 2008) as the platform for qualitative data analysis. During a designated interval of time (usually 2 weeks), each researcher independently coded a portion of the database and then e-mailed the "hermeneutic unit (HU)," the ATLAS.ti term for the coded database, to the team member responsible for retaining and modifying the HU. The HU is an overlying document of the codes that correspond to the underlying primary documents (transcripts). Therefore, all researchers had to maintain the same primary documents, without editing them, once the coding began on those documents.

The researchers independently conducted an initial line-by-line coding of the data. These initial codes and their definitions served as the basis for applying the constant comparative method (Glaser & Strauss, 1967; Strauss & Corbin, 1998) to refine our understanding of the relationships among the data and codes. The team discussed the merits of each code and whether to retain, refine, merge or eliminate each code as warranted. Also, codes were organized on a hierarchical continuum (general/abstract to specific/descriptive). In this way, conceptual families were created as a basis for mapping relationships across the narratives. The team conducted telephonic conversations to process insights from individual analysis and triangulate (Kimchi, Polivka, & Stevenson 1991) this analysis to formulate 20 axial or *parent* codes. This iterative process of text-to-code and code-to-code revision by the researchers not only increased the trustworthiness of our findings (Creswell, 2007; Merriam, 2002) but led to dynamic discussions and opportunities to constantly return to the data and evaluate or confirm our analysis. Additionally, the data from the interviews, observations, and field notes were triangulated in order to provide contextual accuracy. In all, we scheduled 12 conversations to process insights, map out codes and emerging concepts, and challenge each other's analysis. The efforts of the research team, which was made up of two scholars in the field and one Master's-trained research associate, yielded rich perspectives on the salience of spirituality in the lives of people with AD.

In addition to qualitative analysis, descriptive statistics were calculated for all quantitative measures (see Table 2).

Pearson's product-moment correlations were calculated between measures of emotional and behavioral functioning and measures of spirituality (see Table 3).

 ISBN 978-90-04-25205-9

Table 2. *Descriptive Statistics for Quantitative Measures*

	Mean	*SD*	Range
Cognitive			
MMSE (n = 18)	24.33	4.04	13–30
Mood			
Geriatric Depression Scale (n = 20)	3.27	2.58	0–10
Geriatric Anxiety Inventory (n = 18)	1.89	2.69	0–10
Behavior			
Neuropsychiatric Inventory			
Frequency (n = 12)	8.00	5.64	1–16
Severity (n = 12)	10.67	9.65	1–29
Spirituality/Religiosity			
RCOPE-AD			
Positive Scale (n = 24)	11.62	3.29	3–14
Negative Scale (n = 24)	1.17	1.99	0–07
BMMRS-AD			
DSE (n = 23)	10.61	2.15	6–12
VBM (n = 23)	14.30	2.20	9–18
PRP (n = 21)	9.52	3.52	2–14
SRS (n = 20)	3.00	1.52	0–05
RPSS-AD			
Collaborative (n = 23)	8.13	3.96	0–12
Deferring (n = 23)	6.13	4.10	0–12
Self (n = 23)	2.96	3.08	0–09
Santa Clara-AD (n = 24)	17.67	4.72	0–20

Note: Standard Deviation (SD); Brief Religious Coping Inventory-Alzheimer's Disease (RCOPE-AD); Brief Multidimensional Measure of Religiousness and Spirituality-Alzheimer's Disease (BMMRS-AD); DSE (Daily Spiritual Experiences); VB (Values and Beliefs); PRP (Private Religious Practices); SRS (Spiritual and Religious Support); Religious Problem Solving Scale-Alzheimer's Disease (RPSS-AD); The Santa Clara Strength of Religious Faith Questionnaire-Alzheimer's Disease (Santa Clara-AD).

Results

Values and Beliefs

Most participants self-identified as being both religious and spiritual when queried, with only one participant stating that he was not religious and two participants stating that they were not spiritual. Several participants reported that they did not understand the difference between the terms religious and spiritual and considered them the same. On the BMMRS-AD, 52.4% of the participants reported being religious "a lot," and 42.9% reported being religious "some." Sixty-six percent of participants endorsed being spiritual "a lot" and 23.8% endorsed being spiritual "some." Of note,

 ISBN 978-90-04-25205-9

Table 3. *Zero-order Correlations for Measures of Spirituality and Emotional and Behavioral Functioning*

	GDS	GAI	NPIQF	NPIQS
RCOPEpos-AD	.00	−.08	.47	.42
n	22	18	12	12
RCOPEneg-AD	.37^	.52*	.78**	.69*
n	22	18	12	12
Santa Clara-AD	.06	.07	−.43	−.29
n	22	18	12	12
RPSScolab-AD	−.24	−.43^	.50	.50
n	21	17	11	11
RPSSdef-AD	−.01	−.28	.52	.42
n	21	17	11	11
RPSSself-AD	.41^	.24	−.24	−.22
n	21	17	11	11

Note: Geriatric Depression Scale (GDS); Geriatric Anxiety Inventory (GAI); Neuropsychiatric Inventory Frequency Subscale (NPIQF); Neuropsychiatric Inventory Severity Subscale (NPIQS); Brief Religious Coping Inventory Positive Subscale-Alzheimer's Disease (RCOPEpos-AD); Brief Religious Coping Inventory Negative Subscale-Alzheimer's Disease (RCOPEneg-AD); The Santa Clara Strength of Religious Faith Questionnaire-Alzheimer's Disease (Santa Clara-AD); Religious Problem Solving Scale-Collaborative Subscale-Alzheimer's Disease (RPSScolab-AD); Religious Problem Solving Scale-Deferring Subscale-Alzheimer's Disease (RPSSdef-AD); Religious Problem Solving Scale-Self Directing Subscale-Alzheimer's Disease (RPSSself-AD)
** $p < .01$ level (2–tailed) * $p < .05$ level (2–tailed) ^ Non-significant trend

the terms religious and spiritual were used interchangeably by most participants and thus are also used interchangeably in the presentation of our findings.

Several predominant themes emerged when participants were asked to share their most important spiritual or religious beliefs in the context of living with AD. First, they considered these beliefs to be a guide for relating to the world and others. For example, one participant shared how his beliefs allowed him to convey peace and orderliness to future generations: "What does spirituality mean to me? I see it as a driving force. He [God] is the perfection in your life, the peaceful coexistence of striving for orderliness and being an example to my children."

Another participant discussed how his belief system had engendered the value of honesty in his life: "I tie my religion back to my actions and to being an honest person." Another participant eloquently expressed how his beliefs were rooted in his understanding of God's love:

 ISBN 978-90-04-25205-9

> I guess I am really anti-dogma when it comes to religion. I really think that God is a loving God and what Jesus did is great, but the Church turned Jesus' teachings around and trashed them. I think the Church twisted His teachings and diluted the love He was teaching. Jesus would not have any trouble with Buddhism, because it also teaches love.

Second, participants expressed the importance of infusing spirituality into their daily lives. For example, one participant clearly and succinctly expressed a set of beliefs and a sense of mission about sharing these beliefs with others on a daily basis: "I try to please God and do the things that He would want me to do every day. It is my task to bring the word to people who are open to hearing the word." Another participant identified the importance of her daily connection with nature as a source of joy in her life: "I have a very strong connection with nature, very strong. So I just spend a lot of time connecting with nature; it's very pleasant."

Finally, several participants discussed the role spirituality plays in coming to terms with the existential questions brought on by a diagnosis of AD. One individual shared his hopes for a cure for AD:

> You think of people being cured of illness, can this illness be cured the same way cancer might? And could it be cured by a spiritual intervention, a belief in spiritual things, maybe? That could happen, but I am not counting on it. Maybe that is a weak spirituality.

Another individual reflected on his hopes regarding the end of his life and his current stance on euthanasia:

> That's it [referring to his belief in salvation and heaven]. That's why I'm willing to go sooner than my mom did. I've talked to people about it, and they don't want to become a vegetable lying in a bed for 3 years waiting to die. Just let me go.

On the BMMRS-AD, 73.9% of participants endorsed believing that there is a life after death with 26.1% reporting that they were unsure. One woman stated, "I don't think I will have many jewels on my crown, but I think I am going to walk through the pearly gates." Another reported, "I believe that I have a place in this world and in the afterlife." A third person indicated that he believed God would be with him throughout his life, even in the midst of AD, and that he had a strong assurance of an afterlife: "There is a heaven and I am going there. The Lord is with me and beside me all the time."

All of the participants in this sample indicated that their spiritual beliefs remained stable after they were diagnosed with AD with the exception of a few who indicated that their beliefs had strengthened:

 ISBN 978-90-04-25205-9

> Well, I guess my beliefs are stronger. I think that comes with age but also the diagnosis. You think about the end and what is going to happen and your ties with family. God created us to be the best we can, no matter what, and I am trying to be my best self.

Sacred Themes

The significance of spirituality became strikingly clear when people with AD were asked to describe that which was most sacred in their lives. Four major themes emerged: (a) the sacred self; (b) sacred values; (c) sacred relationships; and (d) the transcendent (i.e., God, higher power, spirit) as sacred.

When discussing the self as sacred, participants described their ability to remain independent, their health, and their financial security as most sacred. This theme was evident in the following statement: "Well, the most sacred thing to me is the love and concern I have for myself." The threat to the sacred self could be seen in another participant's concern about losing her independence: "I am scared to death it is going to come to a place where I am going to be dependent on somebody, and I am a very independent person. I have always been independent."

Sacred values, the second theme, included compassion, caring for others, peace, harmony, love, honesty, loyalty, and reliability. For example, one man stated, "Wow, wow. I guess honesty and reli . . . reli . . . being reliable and honest . . . I guess those are the things I think are the most sacred." These sacred values tied back to the deepest spiritual convictions held by participants and could be summed up in this statement: "Well, I think it all boils down to love. I just have a lot of compassion for people now [that I have been diagnosed with dementia] and that is somehow sacred to me."

The third theme pertaining to what people with mild AD consider most sacred was their relationship with others. The spousal relationship and the relationship with adult children were noted most frequently followed by the relationship with grandchildren and friends. A touching account of the importance of one participant's relationship with her daughter follows:

> My salvation is my daughter. If she wasn't with me now I don't know what I would do. She is my strength. Not knocking the Lord out, but she is my day's strength. We do things together. She is here to eat when I invite her . . . and sometimes when I don't. But, she is what's holding me up right now. I know the Lord is involved, and I think He sent her here. She moved here to be with me. That is sacred.

 ISBN 978-90-04-25205-9

The desire to continue contributing to the lives of loved ones in the midst of living with AD is reflected in the following: "What is most sacred to me is to make my wife happy." Another participant expressed his hope to remain loyal to his friends: "The relationship with friends is sacred. Friendships and loyalty and being loyal to friends . . . I guess those are the things that I think are most sacred."

The final theme pertaining to what was most sacred to people with AD was transcendent reality. The subthemes of salvation, grace, worship, religious community, and the beauty of nature emerged within this theme. One participant discussed her desire to become more reliant on God as a sacred quest within the context of living with AD: "What is most sacred to me is that I would learn to rely on God for any help I need." Another individual shared how his assurance of salvation was sacred to him: "My knowledge that Christ has paid the price for my sins and that He has a place for me in heaven when the time comes is most sacred to me."

Most participants did not endorse experiencing a shift in what they considered to be sacred once they were diagnosed with AD. Among those who endorsed a shift, the sacred typically took on greater significance than before the diagnosis. For example, one woman described how important her family become to her initially after her husband was diagnosed with a terminal illness and then again after she was diagnosed with AD:

> Before I moved here, my husband and friends were always first and family was second. And then my family took care of him and now me. I have learned the importance of support, family support, and so now I would have to put that first. This has really taken root since I became the patient. My family has really come through for me.

Relationship with the Transcendent

In this sample, all participants believed in God, although one participant preferred to use the term Spirit to refer to the transcendent. Qualitative analysis revealed four major themes regarding participants' reflections on their relationship with the transcendent: (a) the primacy of this relationship; (b) attributes or characteristics placed on the transcendent; (c) feelings about the transcendent; and (d) perceived ability to connect with the transcendent.

On the Santa Clara-AD, 95.7% of participants reported that their relationship with the transcendent was very important to them, suggesting the primacy of this relationship. If the relationship was considered important prior to the diagnosis, it typically remained important after the diagnosis,

 ISBN 978-90-04-25205-9

suggesting that God-concepts remain stable over time in this population. For example, a participant's lifelong reliance upon and appreciation for her relationship with God follows:

> No, I have always loved God. I grew up that way. When I was an early teen, I didn't particularly. But as I started aging, I realized without God, where would I be? You know, where would any of us be?

Another example came from a participant who reflected on the importance of her relationship with God in her day-to-day life:

> As long as I start my day off with His protection and understanding, He won't lead me the wrong way. If I take a wrong turn, it is going to be my choice, because I am really not paying attention to Him. I feel like He is going to protect me as much as He can.

An example of a participant's increased reliance on her relationship with God, resulting directly from her struggles with AD, was evident in the following quote: "Oh, I probably talk to Him a lot more now than I used to about situations that I've never experienced before, you know, because I come across things every day." No participants reported that their relationship with God became less important after they were diagnosed with AD, although a couple of participants indicated it had always been difficult for them to relate to God. For example, one participant said, "Well, I guess I believe there is a God. Sometimes I feel like it is difficult to relate to Him."

Attributes or characteristics participants placed on God were trustworthy, nurturing, faithful, loving, full of grace, dependable, and best friend. The omnibenevolence or *all goodness* of God was emphasized by participants as they dealt with living with AD. For example, one woman stated, "Whenever I am in trouble or question what to do, I have this bracelet that says, 'God is good enough,' and all I have to do is snap it. He is my inner strength."

Gratitude was the most frequently reported feeling expressed by participants toward God. For example, one individual stated, "You can only be more and more grateful for who God is and what He does. And when you look around and see what is going on, you can only be grateful." This gratitude extended into many areas of life including what had been achieved in the past (i.e., family, friends, finances, career, etc.), what was valued in the present (i.e., family, friends, finances, health, etc.), and hopes for the future (i.e., cure, good death, heaven, etc.). The following statement from one individual captured the depth of gratitude she felt toward God:

 ISBN 978-90-04-25205-9

> Just the whole thing about what God contributed to us and taught us to do. Like being healthy, taking care of ourselves, believing in Him, believing in the angels, and all those things and knowing that God is up there watching over us and knowing that He has given us this world and this life.

The final theme, perceived connection with God, suggested a stable or increasing connection during the mild to moderate stages of AD. For example, one woman shared how this connection had been strengthened after she was diagnosed with AD: "I have more time with Him now. Before it was always busy, busy, busy. I did not have a lot of time for Him. He was always there with me, but I would forget to talk to Him." Several participants reported that the relationship was deeper or stronger. For example, one person stated, "I think it has just deepened." Another individual shared, "Well, I just know it is stronger." Others reported feeling closer to God as seen in these statements: "You know, I tune in more often, and He tunes in with me;" and "Well, I think I have a closer, uh, as they say in the song, a closer walk with Thee;" and "Well, I think the older you get and the closer you get to the end of your life here, you just naturally get closer to God."

In contrast to this generally positive picture, one participant revealed that she had experienced a diminished connection over time, which she attributed to cognitive decline: "It was this connection, this very strong connection I had with the spirit. And now I don't feel it as much." She went on to reflect on a recent experience of connecting with the spirit which was a sacred moment for her:

> I sat down to do a short meditation and sometimes it takes me a long time to get into that space where I feel a connection. However, this time I sat down and closed my eyes, and it was right there. This doesn't happen all the time but enough to keep me feeling that someone is out there.

Poignantly, one individual reflected on whether or not he would still be able to conceptualize God with progression of the disease: "I guess I have thought more about if you lose your cognitive awareness and ability, do you lose your ability to conceive of God?"

Spiritual Practices

Participants were asked about their current spiritual practices and how these practices had been affected by changing cognition. They reflected on both private spiritual practices and corporate spiritual practices (within a formal congregational setting such as a church, synagogue, mosque, or spirituality group).

 ISBN 978-90-04-25205-9

Private practices

The most frequently reported private spiritual practice was prayer. On the BMMRS-AD, 57.1% of participants reported engaging in private prayer on most days with another 33.3% reporting engaging in private prayer on some days. Upon interview, several individuals expressed that they were significantly and consistently devoted to the practice of prayer. For example, one participant stated: "I always pray. Even in those 50 years when I didn't have much to do with the church, I still prayed. And I still pray today." Another participant discussed the continuity of this practice over his life-span: "I say my prayers just like I did when I was a little bitty boy, and I guess the only difference is I don't get on my knees all the time like I did when I was a kid."

Participants described diversity in the forms of prayer practiced. Some individuals reported ritualistic prayer as noted in this participant's statement, "We have prayers before every meal." Other individuals reported participating in petitionary prayer for themselves, "I pray that God helps me" and for others, "I pray that the children will believe and the grandchildren." A meaningful example of an answer to petitionary prayer, for relief from emotional suffering after receiving a diagnosis of Alzheimer's disease, follows:

> I look back at all that, and I think my relationship with God is hopefully very good now, and especially after I made that prayer. It just totally relaxed me. I am serious. It was like there was a steel trash can over my head, over my body, and He lifted it off and put it down. It was a big step.

Narratives about prayer often revealed themes of thanksgiving and praise and tended to be more colloquial or conversational in nature: "I just thank him every night that I'm still alive;" and "Well, yes I pray and I learned that we need to praise God and find joy in Him." An example of a participant's trust in God to compensate for his inability to remember follows:

> I just go in prayer ya know many times a day and I don't feel like He, God cares whether I have ya know the right name I mean, I mean not have a last name but I have given a description of the person, so and so in such a town ya know the best I can then He can see through it and knows what I'm talking about.

Meditation, in addition to prayer, was reported as an important practice in people with mild AD. When reflecting on her meditation practice, one participant stated, "[I] meditate once a day and I don't hear the voice, but I hear God talking to me;" and "I do a morning meditation every day." We noted a particularly insightful report on the practice of meditation by one of the participants:

 ISBN 978-90-04-25205-9

> It got more and more developed when my husband was sick, and I was taking care of him. This time I find that I'm less . . . if I don't meditate I don't feel as lost, whereas when I was taking care of my husband it was almost a desperate need and that was what comforted me and kept me going. It was this connection, this very strong connection I had with the spirit. And now I don't feel it as much. Why, I'm not sure. But I liked to do that in the morning . . . the reality of this picture, the beautiful spiritual picture of the spiritual room with the sunlight coming in and the butterflies out back . . .

Consistent with their reports on the practices of prayer and meditation, some participants reported benefits from reading Scripture: "I get up early in the morning and read my Bible every morning before I start my day." In addition, some participants expressed that reading inspirational texts was helpful in dealing with their struggles with dementia. One woman said:

> I'm a faithful reader of *Guideposts*, and [it tells about] people that have come out of [a struggle]. There are probably a dozen different people that different things have happened to them and how they climb out of whatever it is.

To the extent that singing religious hymns was related to the practice of worship, several participants reported private and corporate involvement in this activity. One narrative reflected the meaningfulness of this practice for dealing with memory loss:

> There's a song that I like to sing, learned to sing that I believe that if I follow it I will be okay. And the song is uh "Joyful, Joyful, We Adore Thee." And I would always tell everyone. And now I'm learning that I need to sing more because my sister said that when I have bad thoughts in my mind that I should sing hymns to God.

A less frequently mentioned spiritual practice was acts of service; nevertheless, a few participants expressed an orientation to service: "And I'm hoping I'm helping others. That's part of being a Christian," one participant said when he discussed his efforts speaking to church groups about living with AD. Another individual had previously served on a committee at her church that was responsible for writing letters to congregants during difficult times. She reported finding a meaningful way to continue to serve in this capacity, even though she was no longer on the committee, by writing inspirational cards to others throughout the year, "I mean I send out 25 cards for every occasion: I mean Halloween, Christmas, Valentine's, Easter, besides illness and death and all that too. So, that is something I can do."

When asked if participants had experienced any changes in their spiritual practices since they began to experience cognitive changes, 97% said

 ISBN 978-90-04-25205-9

they had not had any changes. However, 33% noted an increase in spiritual practices such as prayer: "Oh, I probably talk to Him a lot more now than I used to about situations that I've never experienced before, you know, because I come across things every day"; and "You know, I just pray more uh, more all the time-more frequently, not just right before I go to bed or something."

One participant shared how there was a change in her ability to recall or understand familiar religious texts, suggesting a significant spiritual struggle for her:

> Jeremiah is my favorite, but like right now, I can't tell you what chapter, or what verse or anything, but I do know where it comes from. And there's a lot of things that I'm not real sure where it's coming from: Matthew, Mark, Luke or John . . . but these statements, and I may not say exactly if it's written in the Bible, but I've noticed there's a lot of things I've been reading it doesn't say exactly the same words they do, different things.

Corporate practices

All participants reported that they were involved, at least historically, with a spiritual or religious community, and many had an interest in maintaining their level of involvement. For example: "In terms of religious practices, we have a little bit more time to go to church, so it has that dimension for us." The importance of involvement was reflected by another participant's statement, "Well I'm not particularly religious. I go to church every Sunday and I'm not a shoutin' Baptist or anything, but I recognize who my savior is. I believe it has been the one reason that I have survived."

Participants were also asked to report the extent to which their pattern of involvement or noninvolvement affected their experience with memory loss. Five (17.9%) stated that their involvement had increased since being aware of their memory loss as reflected in these statements: "Well except we are going to church more," and "Now that I'm older, my wife is an ex-Catholic nun and I'm a lax Episcopalian so we've kind of re-signed back up with the Episcopal Church." One participant attributed greater involvement to his loss of a job: "Well only from the perspective that since I lost my job I have more free time to be at the church to work on stuff."

Decreased level of involvement was reported by 53.6% of participants. For example: "Well, we just attend church services. And I mean I used to be on every committee and all the boards and all the blah, blah, you know, Sunday School teacher." Several participants stated that age, a physical challenge, and/or a lack of transportation hindered their participation as noted in the following:

 ISBN 978-90-04-25205-9

> They have church down here. I have gone a few times but not always. I was having trouble walking and then someone had to take me in a wheelchair, which a lot of them are in wheelchairs. I have not gone as much. But I've loved being involved with that for many years. I mean that's kind of where it started in church. It's been that way for a long time. I mean I can't at my age keep doing every single thing. But other than that I'm still involved in—I mean, you know, it's going down because of my age.

Several participants reported that transportation issues had significantly impeded their ability to stay actively involved with their spiritual communities. When asked why she had stopped attending worship service, one woman said, "Because you can't, uh well I can't drive." Another woman said, "But it's hard to go more than just on Sunday since I don't drive anymore" when expressing her disappointment in her decreased congregational involvement.

One approach to overcoming the barriers to attendance was to rely on television: "I try to listen on TV to the Mass every Sunday" and

> They have a church thing on TV. I try, because I try to keep up with church as much as I can. I don't do it perfect. And I don't do it all the time. But I've always believed in church.

Another participant illustrated how television broadcasts allowed her to continue to express her interest in congregational involvement:

> I own a TV. And you get a, quite a bit out of that. On Sunday you really do. And I try, and I can't drive, so if my husband's not able to take me or nobody else is, I flip on that. Because I know, you know, because without that, without God, where would we be?

The decrease in participation in the life of the congregation was also manifested in the withdrawal from specific tasks that, at one time, defined the person's role in the congregation. Consider these illustrations of role loss: "Now my personal belief system has been still there, it is just that the activity, I was, I didn't feel like I should be a leader in that area, so I did not do anything." The decrease in meaningful engagement was particularly evident in this report:

> I want to say maybe 40 years ago or 50 years ago when I was going to church I was going to the early service, and I was in charge of getting everything arranged and up on the mantel and stuff like that. And I was very, you know, I knew what was going on with the church at what-have-you, and now I'm just going to church. I was very involved in what they were doing and now when something came up here not last year, but a couple of years before they (would) call me up and get my opinion on something. But, right now I'm just lucky to go to church.

 ISBN 978-90-04-25205-9

Several participants noted that their religious community was a source of encouragement and help to them:

> It's a great family. It's a total family. A lot of churches become such a mega-church that you don't know one-tenth of all the people that are there. We have a congregation of around 30 something people and most of them are pretty frequent attendees so you get to know them and their families and then we do all kinds of stuff on the fun side too that kind of endears families sometimes, and it's fun to go meet church families on trips too and stuff.

Others had similar comments: "Everybody's pretty nice to me. You know, and I enjoy hearing the preacher preach . . . and I love the little ones who make it up there and do their little thing. You know, on the stage. I love that." The benefit of small group activities like Sunday School was evident in this quote:

> We just we have a wonderful Sunday school class. It is very supportive, and we have several that have Alzheimer's that are much more progressed than I, and I feel one in particular is in complete denial. He is out there driving, and we've seen one catastrophe after another, but he doesn't have family in town.

Some participants reported a change in their sense of belonging in their religious or spiritual communities since being diagnosed with Alzheimer's disease: "My involvement has changed, because I don't go. You don't fit. When someone asks you things like what county are you in and you can't tell them, that's a change." For one participant, a life-long pattern of discomfort with congregational involvement was exacerbated in the context of living with Alzheimer's disease leading to a profound sense of loneliness:

> I don't feel comfortable about attending all their dinners and things. There are certain people in that church I love dearly, but there's some I really don't know. I haven't gotten the chance to. And I don't want to do . . ., and I try to, I kind of feel, like in my younger days when I was trying to find a shadow to hide in. But, I saw a portrait one time that said I can be in a crowd but be alone. And that's how I am. In most places, I feel uncomfortable, and I feel alone. And I won't step forward and change it. I'm just locked into that one.

Spiritual Coping

The RPSS-AD was utilized to identify spiritual problem solving strategies in participants with mild AD. Statements from the collaborative religious coping scale were endorsed at the highest mean level (M = 8.13; SD = 3.96),

 ISBN 978-90-04-25205-9

followed by statements from the deferring religious coping scale (M = 6.13; SD = 4.10) and statements from the self-directed religious coping scale (M = 2.96; SD = 3.08). The most frequently endorsed item from the collaborative religious coping scale was, "God and I together put my plans into action." The most frequently endorsed item from the deferring religious coping scale was, "I wait for God to decide what it means to me when a situation makes me anxious." The most frequently endorsed items from the self-directed religious coping scale were, "I make choices independent of God when deciding on a solution" and "I try to come up with possible solutions without God's help." See Table 4 for percent distribution of item responses on the RPSS-AD.

An example of a collaborative religious coping statement from a participant interview as it relates to living with AD follows: "Oh, I probably talk to Him a lot more now than I used to about situations that I've never experienced before, you know, because I come across things every day." An example of a deferring religious coping statement from a participant interview follows: "What is most sacred to me is that I would learn to rely on God for any help that I need." No examples were identified of self-directed religious coping statements in the participant interviews.

The Brief RCOPE-AD was utilized to examine positive and negative religious coping strategies in participants. In this sample, positive religious coping (M = 11.62, SD = 3.29) was endorsed at greater mean levels than negative religious coping (M = 1.17, SD = 1.99). The most frequently endorsed item from the positive religious coping scale was, "Sought God's love and care." The most frequently endorsed items from the negative religious coping scale were, "Wondered whether God had abandoned me" and "Wondered what I did for God to punish me." See Table 5 for percent distribution of item responses. Participants did not spontaneously verbalize any examples of negative religious coping during their interviews.

Finally, we were interested in the relationship between religious coping, mood, and behavior in persons with AD. We hypothesized that individuals who utilized negative religious coping strategies to a greater degree would experience more symptoms of anxiety, depression, and behavioral changes than those who utilized positive religious coping strategies. The GAI, which assesses for symptoms of anxiety, was positively correlated with the negative religious coping scale of the Brief RCOPE-AD (r[16] = .52, p = .03). Frequency of behavioral and psychological symptoms of dementia (BPSD), as measured by the frequency subscale of the NPIQ, was highly correlated with the negative religious coping scale of the Brief RCOPE-

 ISBN 978-90-04-25205-9

Table 4. *Percent Distribution of Item Responses for RPSS-AD*

	Not at all	A little	A lot
Collaborative			
1. God and I work as partners to solve my problems.	13.0	21.7	65.2
2. God and I decide together what my problems mean.	21.7	39.1	39.1
3. God and I put my plans into action.	8.7	21.7	69.6
4. God and I work together to think of solutions to my problems.	21.7	26.1	52.2
5. I work with God to make sense of things after solving a problem.	21.7	17.4	60.9
6. I work together with God to find ways to relieve my worries if I am nervous about a problem.	30.4	21.7	47.8
Deferring			
1. God provides solutions to my problems; I don't have to think about solving them myself.	30.4	21.7	47.8
2. I wait for God to decide what it means for me when a situation makes me anxious.	26.1	47.8	26.1
3. God makes sense of my troubles; I don't spend much time thinking about making sense of them myself.	30.4	17.4	52.2
4. I let God decide on how to deal with my problems rather than trying to come up with my own solutions.	39.1	47.8	13.0
5. I wait for God to take control and work things out when it comes to solving my problems.	34.8	43.5	21.7
6. I leave it up to God to decide the meaning of troublesome issues.	39.1	30.4	30.4
Self-Directing			
1. I decide what it means without God's help when I have difficulties.	56.2	43.5	0.0
2. I make choices independent from God when deciding on a solution.	52.2	39.1	8.7
3. I deal with my feelings without God's help when I am faced with trouble.	65.2	26.1	8.7
4. I try to come up with possible solutions to difficulties without God's help.	52.2	26.1	21.7
5. I act to solve my problems without God's help.	73.9	17.4	8.7
6. I try to make sense of rough times without relying on God.	69.6	21.7	8.7

Note: $n = 23$

 ISBN 978-90-04-25205-9

Table 5. *Percent Distribution of Religious Coping Item Responses for RCOPE-AD*

	Not at all	A little	A lot
Positive Religious Coping Items			
1. Looked for a stronger connection with God	8.3	12.5	79.2
2. Sought God's love and care	0.0	16.7	83.3
3. Sought help from God in letting go of my anger	12.5	12.5	75.0
4. Tried to put my plans into action together with God	4.2	25.0	70.8
5. Tried to see how God might be trying to strengthen me in this situation	12.5	16.7	70.8
6. Asked for forgiveness from God	8.3	4.2	87.5
7. Focused on my religion to stop worrying about problems	16.7	25.0	58.3
Negative Religious Coping Items			
8. Wondered whether God had abandoned me	79.2	12.5	8.3
9. Felt punished by God	87.5	0.0	12.5
10. Wondered what I did for God to punish me	79.2	4.2	16.7
11. Questioned God's love for me	95.8	4.2	0.0
12. Wondered whether my religious community abandoned me	83.3	8.3	8.3
13. Decided the devil made this happen	87.5	8.3	4.2
14. Questioned the power of God	91.7	8.3	0.0

Note: $n = 24$

AD ($r[10] = .78$, $p = .00$). Similarly, there was a strong positive association between the severity subscale of the NPIQ and the negative religious coping scale from the Brief RCOPE-AD ($r[10] = .69$, $p = .01$). There was a positive but non-significant trend association for symptoms of depression, as measured by the GDS, and the negative religious coping scale of the Brief RCOPE-AD ($r[20] = .37$, $p = ns$). There was also a negative but non-significant trend association between the GAI and the collaborative religious coping scale on the RPSS-AD ($r[15] = -.43$, $p = ns$).

Discussion

Previous research suggests that religious or spiritual beliefs and practices are associated with higher levels of cognitive functioning and reduced incidence of behavioral changes in people with AD (Kaufman et al., 2007; Hill et al., 2006). To date, systematic explanations of these associations, based on the reports of people with AD, have not been available. Through the unique lens of changing cognition, 28 people with mild AD provided

 ISBN 978-90-04-25205-9

first-hand narrative accounts of how their spirituality influenced their adaptation to living with this disease. They offered reflections on their core values and beliefs, how these values and beliefs were expressed, what they considered most sacred, and how they utilized their spiritual resources to cope with living with AD. Our findings verify the importance of spirituality in adapting to living with mild AD, provide initial observations about how spiritual values and beliefs are experienced and enacted by people with AD, and serve as a launching pad for additional research.

Given that changes in the ability to self-initiate is a common symptom of AD, many individuals with AD can benefit from the help of others to facilitate conversations about spirituality and faith. They can benefit from the assistance of others to facilitate these discussions due to changes in the ability to self-initiate. Typically, values and beliefs remain consistent before and after an individual is diagnosed with AD, thus providing others a familiar repertoire for engaging people with mild AD in discussion. Spiritual values and beliefs assist people with AD in coping with the disease by providing them with effective standards for living and relating, models for responding to human suffering, comfort pertaining to their life circumstances, hope for a cure and a good death, courage to continue living life to the fullest, and expectations for an afterlife where they will be fully restored. Health care practitioners, as well as faith communities, must not buy into the idea that people with AD are unable to engage in or benefit from discussing matters of spirituality and faith. To do so would result in denying them a core aspect of their humanity which is vital to their personal identities, worldviews, and ability to make meaning in the midst of this terminal disease.

According to Pargament (1999), spirituality can be defined as "a search for the sacred" (p. 12) in which some individuals view the sacred as transcendent reality or that which is beyond the self as in higher powers, supernatural beings, or guiding life philosophies. Others see the sacred in ordinary day-to-day encounters with people, places, objects, and images that they imbue with meaning. As such, the sacred may be experienced within and through these everyday occurrences via the process of *sanctification* or viewing certain aspects of life through a *sacred lens* (Pargament & Mahoney, 2005). The role of sanctification becomes strikingly clear in the lives of people with AD as they elaborate on what they consider to be sacred, most notably their close relationships with others. These sacred relationships become increasingly important as people with AD begin to lose connections with the past and have difficulty forging connections with the future. Family, friends, and spiritual communities

 ISBN 978-90-04-25205-9

can serve as conduits for reminding people with AD about their unique spiritual heritages, personal attributes and history, and continued worth as individuals. A spiritual development task for people with AD may be to rest in the knowledge that their identities and generativity will continue to live on through these sacred relationships even in the midst of profound memory loss.

A relationship with God or the transcendent remains important to persons with mild AD and serves as a significant resource for coping. This relationship is generally viewed as positive with an emphasis on the omnibenevolence of God and gratitude towards God. People with mild AD typically report that their relationship with God remains stable or strengthens as compared to before the diagnosis and that there is an increased reliance upon this relationship in day-to-day life. However, it is unclear how this relationship is actually experienced by people with AD as the disease progresses, given profound changes in verbal communication, which is a significant spiritual concern expressed by some people with mild AD. Additional research needs to be conducted on the experience and expression of spirituality in the later stages of AD.

Spiritual practices are salient to people with mild AD both before and after the diagnosis. According to MacIntyre (1984), spiritual practices are enacted to achieve valued outcomes and are based on what is considered virtuous to the person. The outcomes of practices are expressed as external goods (a supportive religious community, corporate recognition) or internal goods (attitudes, values, habits, feelings, and understandings) that are uniquely associated with each practice. Dykstra (1999), writing from a Christian perspective, provided a list of practices associated with a Christian life of faith: worshipping, telling the Christian story, considering Scripture, praying, confessing and forgiving, tolerating and encouraging one another, serving, giving and receiving gifts, suffering for others, providing hospitality, resisting social and economic injustice, and working together to sustain life in the world. In this study, people with mild AD reported engaging in five of Dykstra's spiritual practices, including congregational involvement, telling the Christian story, interpreting Scripture, praying, and serving. They associated their spiritual practices with positive outcomes such as a closer relationship with God and a sense of contribution to the work of God through their religious communities.

In general, private spiritual practices were maintained to the extent possible once an individual is diagnosed with AD and in some instances increased in expression (which was true for the practice of prayer). However, changes in cognitive functioning may profoundly impact the ability

 ISBN 978-90-04-25205-9

to sustain customary performance when participating in private spiritual practices which may serve as a source of frustration for people with AD. Examples are forgetting the names of people the person with AD is praying for and difficulty recalling Scripture.

People with mild AD demonstrated remarkable motivation to continue engaging with their faith communities despite the fact that reduced access and declining capacities created significant barriers to involvement. Difficulty negotiating the personal, relational, and structural aspects of congregational life was embedded in the narratives of people with mild AD with most attributing these difficulties to aging or poor health rather than cognitive decline. Glimpses of deep personal struggle were evident by some who expressed a sense of abandonment by their faith communities. It became clear that faith communities can have a profound influence on helping or hindering people with AD in coping with the disease through their willingness to fully embrace people with AD and remove barriers to participation in the community.

Spiritual coping, as defined by Pargament (1997), is an effort to understand and deal with life stressors in ways related to the sacred. Spiritual coping can be helpful to individuals as they navigate challenging life circumstances or serve as a barrier to health and wellbeing depending on the form and function it takes (see Lavelock, Griffin, & Worthington, 2013 [this volume]). Spiritual struggle, or maladaptive spiritual coping, has been associated with poorer health outcomes (Ano & Vasconcelles, 2005; Exline & Rose, 2005; Fitchett & Risk, 2009; Pargament, Murray-Swank, Magyar-Russell, & Ano, 2005) in women with breast cancer (Thuné-Boyle, Stygall, Keshtgar, Davidson, & Newman, 2011), adults with end-stage renal disease (Ramirez et al. 2012), and older adults with functional limitations (Pargament, Koenig, Tarakeshwar, & Hahn, 2004).

In this study, there was a positive relationship between the self-report measure of spiritual struggle (i.e., negative religious coping) and the self-report measure of anxiety. Also, there was a non-significant trend relationship between the self-report measure of spiritual struggle and the self-report measure of depression. These findings suggest that people with mild AD may be similar to other medical populations in that spiritual struggle and reduced mood go hand in hand and should be addressed by professional caregivers. Feelings of abandonment by God and by one's religious community, as well as being inflicted with dementia as a punishment from God, were the most frequently endorsed items on the Brief RCOPE-AD. Of note, these concerns were not expressed during the interview process but were endorsed on a quantitative measure. Professionals

 ISBN 978-90-04-25205-9

who work with people with mild AD may wish to use surveys to get at these potential struggles, as it may be difficult for them to report these struggles due to embarrassment or wanting to please the health care professionals with their responses. Validating and normalizing these thoughts and feelings may be particularly beneficial for people with AD as they try to work through the deep existential questions that may surface as a result of this diagnosis. From a clinical and pastoral perspective, people with AD should be assured that God did not inflict this disease upon them and that the disease does not reflect a shortcoming on their part. The spiritual community can serve to encourage, support, and facilitate continued involvement which may serve to decrease feelings of punishment and abandonment.

There was a very strong positive relationship between the self-report measure of spiritual struggle and the two informant report measures of behavioral and psychological symptoms of dementia. This finding is notable for several reasons. First, addressing the deep existential concerns experienced by people with AD may indeed lead to better behavioral and psychological outcomes (as noted by their family members). Second, better behavioral and psychological outcomes in persons with AD could lead to decreased burden, stress, and distress on the part of family members and presumably reduce the need for psychotropic medication use in this vulnerable population. Third, with disease progression, most people with AD experience an increase in behavioral and psychological symptoms. These symptoms tend to be most prominent during the moderate stages of AD (especially during the mild to moderate shift). Additional research is needed to determine the trajectories of spiritual struggle as it relates to behavioral and psychological changes with disease progression.

Conclusions

The current study has several notable limitations. Given that the sample size was small, the quantitative data should be replicated with a larger sample. Many of the bivariate associations between variables were in fact quite strong; nevertheless, they did not reach statistical significance due to lack of statistical power (see Table 3). For the qualitative data, data saturation was reached and findings were therefore robust, although additional interviews should be conducted with people with AD from diverse cultural and spiritual backgrounds. Additionally, spirituality should be examined in people with other forms of dementia given unique neuro-

 ISBN 978-90-04-25205-9

logical profiles, expression, and progression. Finally, although individuals were invited to participate in a general study on health and well-being in people with mild AD, they were informed that the study would include questions pertaining to religion or spirituality. Therefore, our findings may have been biased in that only those who were interested in or comfortable discussing these topics agreed to participate.

Despite these limitations, several conclusions and recommendations are provided for clinical practice and research. First, there is a need for spiritually integrated assessment in clinical and pastoral practice for people with AD. For example, health care providers and chaplains should consider integrating clinical interview questions and standardized measures of spiritual functioning into their assessments of people with AD. In this study, it was demonstrated that individuals with mild AD can engage in meaningful discussion about their spiritual values and beliefs, practices, resources, struggles, and concerns through open-ended questions, such as those posed in the DLD interview (see Appendix A), allowing for a unique understanding of their personal experience. Likewise, quantitative measures of spirituality can be effectively adapted for use with individuals with AD and others who have diminished cognition (See Appendix B for recommended adaptations). Finally, traditional neuropsychological evaluation may be utilized to identify how to best adapt spiritually oriented activities in order to maximize comprehension and ability to participate for people with AD. For example, if it is determined that an individual's memory for visually presented information is better than memory for verbally presented information, pastors or religious educators can begin to integrate visual cues and representations into their presentations so that people with AD and other dementias can fully benefit.

Integrating spirituality into clinical interventions for people with mild AD may be effective in decreasing some of the emotional and behavioral symptoms of AD, especially when people with AD are experiencing spiritual struggles. The reactions of many participants to the DLD interview were positive and viewed as a meaningful opportunity to share their deepest beliefs and concerns. At least one person with mild AD stated that the interview allowed her to "feel like a person again," and others reported that the interview process had been therapeutic. In this sense, the DLD may serve as the foundation for a spiritually integrated intervention for coping with AD (which the authors are in the process of developing).

Once religious or spiritual resources are identified, clinicians can work to reduce barriers to accessing these resources for people with mild AD. First, clinicians can suggest alternate modes of transportation so people

 ISBN 978-90-04-25205-9

with mild AD can continue to be engaged with their faith communities. Lack of consistent transportation was the most frequently reported barrier to spiritual resources by the participants of this study. Families and members of faith communities may inadvertently underestimate how much people with mild AD value continued involvement.

Clinicians can contact spiritual leaders and congregants on behalf of people with AD to provide education on the importance of continuing to include them in the life of the congregation and provide suggestions for modifications needed to facilitate participation. For example, a person with mild AD came for counseling with one of the researchers and indicated that she was depressed, because she was no longer allowed to help with Children's Church on Sunday mornings. She had participated in this ministry for over 50 years and experienced this change of status as a significant loss. After contacting the pastor, it was determined that some people in the congregation thought that AD was contagious and were afraid for their children. After receiving education on the etiology of AD, the pastor and congregation allowed her to resume her position contributing to Children's Church, and her depression lifted. Likewise, clinicians can work with family members, who may inadvertently believe and perpetuate some of the negative stereotypes associated with AD. Clinicians must be aware that some family members have concerns about being judged based on their loved one's changing cognition and behavior and that these concerns can lead to decreased congregational involvement and subsequent isolation and emotional dysfunction and significant loss for family members of people with AD. Again, education is the key in this scenario, and clinicians can encourage family members to share their experience and needs and concerns with pastors and fellow congregants.

In conclusion, there is rich opportunity for further research around the spiritual dimensions of living with dementia. Future work should include gaining a better understanding of spirituality among people who have been diagnosed with different types of dementia (i.e., AD versus FTD), across the course of dementia (from diagnosis to death), and across diverse social, ethnic, and religious cultures. For people with mild AD, their spirituality and faith may truly serve as a solid foundation from which to stand, as a rock, in the uncertainty of this disease.

 ISBN 978-90-04-25205-9

Appendix A

Dimensions of Living with Dementia Interview (McGee and Carlson, 2011)

Section B: Spiritual/Religious Dimensions of Living with Dementia

1. What do you hold as most sacred in your life? Has this changed at all since you were diagnosed with dementia? If so, how?
2. What are your most important spiritual/religious beliefs? Have they changed at all since you were diagnosed? If so, how?
3. How would you describe your relationship with God (e.g. use words like Divine, Spirit, higher power if needed)? Has this changed at all since you were diagnosed? If so, how?
4. Tell me about your current spiritual/religious practices. Have they changed at all since you were diagnosed? If so, how?
5. Tell me about your current involvement with your religious/spiritual community. Has this changed at all since you were diagnosed? If so, how?
6. What Scripture or religious/spiritual teachings have been most helpful to you in dealing with dementia, if any?
7. Have there been any Scripture or religious/spiritual teachings that have made it more difficult for? If so, which ones?
8. Have you had any religious/spiritual struggles since you were diagnosed? Can you tell me about it?

Note: Please contact first author for copy of entire interview if interested.

 ISBN 978-90-04-25205-9

Appendix B

Adaptations to Measures of Religiosity or Spirituality

1) All measures were administered by a trained examiner as opposed to completed independently.
2) Each question was presented both verbally and visually to maximize comprehension.
3) A stimulus book with each item written out in large font at the top of each page was utilized in order to minimize the need to rely on short-term memory while contemplating each item.
4) Color coded response choices were placed below each item on the bottom of each page of the stimulus book to provide visual cues for response choices.
5) Participants were asked to verbalize and point to their answer for each question (thus maximizing the likelihood that those with expressive language difficulties could complete the measures).
6) The number of response choices on the Likert scales for each measure, which ranged from 3–9, was decreased to 3 for consistency.

References

Allen, R.S., Hilgeman, M.M., Ege, M.A., Shuster, J.L. Jr., & Burgio, L.D. (2008). Legacy activities as interventions approaching the end of life. *Journal of Palliative Medicine, 11*(7), 1029–1038. doi:10.1089/jpm.2008.0002

Alzheimer's Association. (2011). Alzheimer's disease facts and figures. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association, 7*, 208–244. doi:10.1016/j.jalz.2011.02.004

American Psychiatric Association . (2000). *Diagnostic and statistical manual of mental disorders* (4th Ed., text rev.). Washington, DC: American Psychiatric Association.

Ano, G.G., & Vasconcelles, E.B. (2005). Religious coping and psychological adjustment to stress: A meta-analysis. *Journal of Clinical Psychology, 61*(4), 461–480. doi:10.1002/jclp.20049

Burke, W.J., Nitcher, R.L., Roccaforte, W.H., & Wengel, S.P. (1992). A prospective evaluation of the Geriatric Depression Scale in an outpatient geriatric assessment center. *Journal of the American Geriatrics Society, 40*(12), 1227–1230. http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1532-5415

Bush, A.L., Jameson, J.P., Barrera, T., Phillips, L., Lachner, N., Evans, G., . . . Stanley, M.A. (2012). An evaluation of the Brief Multidimensional Measure of Religiousness/Spirituality in older patients with prior depression or anxiety. *Mental Health, Religion, & Culture, 15*(2), 191–203. doi:10.1080/13674676.2011.566263

Coin, A., Perissinotto, E., Najjar, M., Girardi, A., Inelmen, E. M., Enzi, G., . . . Sergi, G. (2010). Does religiosity protect against cognitive and behavioral decline in Alzheimer's dementia? *Current Alzheimer Research, 7*(5), 445–452. doi:10.2174/156720510791383886

Creswell, J. (2007). *Qualitative inquiry and research design. Choosing among five traditions* (2nd ed.). Thousand Oaks, CA: Sage Publications.

Cummings, J.L., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D.A., & Gornbein, J. (1994). The neuropsychiatric inventory: Comprehensive assessment of psychopathology in dementia. *Neurology, 44*, 23–14. doi:10.1212/WNL.44.12.2308

Dykstra, C. (1999). *Growing in the life of faith: Education and Christian practices*. Louisville, KY: Geneva Press.

 ISBN 978-90-04-25205-9

Evans, S., & Katona, C. (1993). Epidemiology of depressive symptoms in elderly primary care attendees. *Dementia, 4*(6), 327–333. doi:10.1159/000107341

Exline, J.J., & Rose, E. (2005). Religious and spiritual struggles. In R.F. Paloutzian & C.L. Park (Eds.). *The handbook of the psychology of religion and health* (pp. 315–330). New York, NY: Guilford Press.

Fetzer Institute and the National Institute on Aging Working Group (1999). *Multidimensional measurement of religiousness/spirituality for use in health research*. Kalamazoo, MI: John E. Fetzer Institute.

Fillenbaum, C.G., Heyman, A., Huber, M.S., Woodbury, M.A., Leiss, J., Schamder, K.E., . . . Trapp-Moen, B. (1998). The prevalence and 3–year incidence of dementia in older black and white community residents. *Journal of Clinical Epidemiology, 51*, 587–595. doi:10.1016/S0895-4356(98)00024-9

Fitchett, G., & Risk, J.L. (2009). Screening for spiritual struggle. *Journal of Pastoral Care and Counseling, 63*, 4–12. http://www.jpcp.org/jpcc.htm

Folstein, M.F., Folstein, S.E., & McHugh, P.R. (1975). "Mini-Mental State": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*(3), 189–198. doi:10.1016/0022-3956(75)90026-6

Fox, C.A., Blanton, P.W., & Morris, M.L. (1998). Religious problem-solving styles: Three styles revisited. *Journal for the Scientific Study of Religion, 37*, 673–677. doi:10.2307/1388148

Freiheit, S.R., Sonstegard, K., Schmitt, A., & Vye, C. (2006). Religiosity and spirituality: A psychometric evaluation of the Santa Clara Strength of Religious Faith Questionnaire. *Pastoral Psychology, 55*(1), 27–33. doi:10.1007/s11089-006-0029-y

Glaser, B.G. & Strauss, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine.

Hebert, L.E., Scherr, P.A., Bienias, J.L., Bennett, D.A., & Evans, D.A. (2003). Alzheimer's disease in the US population: Prevalence estimates using the 2000 census. *Archives of Neurology, 60*(8), 1119–1122. doi:10.1001/archneur.60.8.1119

Hill, T.D. (2006). Religion, spirituality, and healthy cognitive aging. *Southern Medical Association: Special Section on Spirituality/Medicine Interface Project, 99*(10), 1176–1177. doi:10.1097/01.smj.0000242747.71884.66

Hill, T.D., Burdette, A.M., & Angel, J.L., & Angel, R.J. (2006). Religious attendance and cognitive functioning among older Mexican Americans. *Journal of Gerontology: Psychological Science, Social Science, 61*(1), 3–9. Retrieved from http://psychsocgerontology.oxfordjournals.org/content/61/1/P3.full

Holmes, C., Cairns, N., Lantos, P., & Mann, A. (1999). Validity of current clinical criteria for Alzheimer's disease, vascular dementia, and dementia with Lewy bodies. *British Journal of Psychiatry, 174*, 45–50. doi:10.1192/bjp.174.1.45

Idler, E.L., Musick, M.A., Ellison, C.G., George, L.K., Krause, N., Ory, M. G., . . . Williams, D. R. (2003). Measuring the multiple dimensions of religion and spirituality for health research: Conceptual background and findings from the 1998 General Social Survey. *Research on Aging, 25*, 327–363. doi:10.1177/0164027503025004001

Kaufman, Y., Anaki, D., Binns, M., & Freedman, M. (2007). Cognitive decline in Alzheimer's disease: Impact of spirituality, religiosity, QOL. *Neurology, 68*(18), 1509–1514. doi:10.1212/01.wnl.0000260697.66617.59

Kimchi, J., Polivka, B., & Stevenson, J. S. (1991). Triangulation: Operational definitions. *Nursing Research, 40*(6), 364–366. doi:10.1097/00006199-199111000-00009

Lavelock, C.R., Griffin, B.J., & Worthington, Jr., E.L. (2013). Forgiveness, religiousness, spirituality, and health in people with physical challenges: A review and a model. *Research in the Social Scientific Study of Religion* (*24*), http://www.brill.com/publications/research-social-scientific-study-religion

Levine, E.G., & Targ, E. (2002). Spiritual correlates of functional well-being in women with breast cancer. *Integrative Cancer Therapies, 1*(2), 166–174. doi:10.1177/1534735402001002008

 ISBN 978-90-04-25205-9

Lim, A., Tsuang, D., Kukull, W., Nochlin, D., Leverenz, J., McCormick, W., . . . Larson, E.B. (1999). Cliniconeuropathological correlation of Alzheimer's disease in a community-based case series. *Journal of the American Geriatrics Society, 47*, 564–569. http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1532-5415

Luskin, F. (2000). Review of the effect of spiritual and religious factors on mortality and morbidity with a focus on cardiovascular and pulmonary disease. *Journal of Cardiopulmonary Rehabilitation, 20*(1), 8–15. doi:10.1097/00008483-200001000-00002

MacIntyre, A. (1984). *After virtue: A study in moral theory* (2nd Ed.). Notre Dame, IN: University of Notre Dame Press.

McCullough, M.E., Hoyt, W.T., Larson, D.B., Koenig, H.G., & Thoresen, C. (2000). Religious involvement and mortality: A meta-analytic review. *Health Psychology, 19*(3), 211–222. doi:10.1037//0278-6133.19.3.211

McGee, J.S. (2012). God moments. Retrieved from http://palmerchurch.org/ministry/who-we-are/god-moments/27/

McGee, J.S. & Bratkovich, K.L. (2011). Assessment and cognitive-behaviorally oriented interventions for older adults with dementia. In K.H. Sorocco and S. Lauderdale (Eds.), *Cognitive behavior therapy with older adults: Innovations across settings.* New York, NY: Springer Publishing Company.

McGee, J.S. & Carlson, H.C. (2011). *The Dimensions of Living with Dementia Interview*. Manuscript in preparation.

McGivney, S.A., Mulvihill, M., & Taylor, B. (1994). Validating the GDS depression screen in the nursing home. *Journal of the American Geriatrics Society, 42*(5), 490–492. http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1532-5415

Merriam, S.B. (2002). Assessing and evaluating qualitative research. In S.B. Merriam (Ed.), *Qualitative research in practice: Examples for discussion and analysis* (pp. 18–33). San Francisco, CA: Jossey-Bass.

Mueller, P.S., Plevak, D.J., & Rummans, T.A. (2001). Religious involvement, spirituality, and medicine: Implications for clinical practice. *Mayo Clinical Proceedings, 76*(12), 1225–1235. doi:10.1016/S0025-6196(11)62799-7

Muhr, T. (2008). ATLAS.ti 6.0 [version 6]. Berlin, Germany: Scientific Software Development GmbH.

Pachana, N.A., Byrne, G.J., Siddle, H., Koloski, N., Harley, E., & Arnold, E. (2006). Development and validation of the Geriatric Anxiety Inventory. *International Psychogeriatrics, 19*(1), 1–12. doi:10.1017/S1041610206003504

Pargament, K.I. (1997). Psychology of religious coping. New York, NY: Guilford Press.

Pargament, K.I. (1999). The psychology of religion and spirituality? Yes and no. *International Journal for the Psychology of Religion, 9*(1), 3–16. doi:10.1207/s15327582ijpr0901_2

Pargament, K.I., Kennell, J., Hathaway, W., Grevengoed, N., Newman, J., & Jones, W. (1988). Religion and the problem solving process: Three styles of coping. *Journal for the Scientific Study of Religion, 27*(1), 90–104 .doi:10.2307/1387404

Pargament, K.I., Koenig, H.G., Tarakeshwar, N., & Hahn, J. (2004). Religious coping methods as predictors of psychological, physical, and spiritual outcomes among medically ill elderly patients: A 2–year longitudinal study. *Journal of Health Psychology, 9*(6), 713–730. doi:10.1177/1359105304045366

Pargament, K. I., & Mahoney, A. (2005). Sacred matters: Sanctification as a vital topic for the psychology of religion. *International Journal for the Psychology of Religion, 15*(3), 179–198. doi:10.1207/s15327582ijpr1503_1

Pargament, K.I., Murray-Swank, N., Magyar-Russell, G.M., & Ano, G. (2005). Spiritual struggle: A phenomenon of interest to psychology of religion. In W.R. Miller and H. Delaney (Eds.), *Judeo-Christian perspectives on psychology: Human nature, motivation, and change* (pp. 245–268). Washington, DC: American Psychological Association.

Pargament, K.I., Smith, B.W., Koenig, H.G., & Perez, L. (1998). Patterns of positive and negative religious coping with major life stressors. *Journal for the Scientific Study of Religion, 37*(4), 710–724. doi:10.2307/1388152

 ISBN 978-90-04-25205-9

Plante, T.G., & Boccaccini, M.T. (1997). The Santa Clara Strength of Religious Faith Questionnaire. *Pastoral Psychology, 45*(5), 375–387. doi:10.1007/BF02230993

Plante, T.G., Vallaeys, C.L., Sherman, A.C., & Wallston, K.A. (2002). The development of a brief version of the Santa Clara Strength of Religious Faith Questionnaire. *Pastoral Psychology, 50*(5), 359–368. doi:10.1023/A:1014413720710

Prince, M., Bryce, R., Ferri, C. (2011). *World Alzheimer's report 2011*. Retrieved from http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf

Ramirez, S.P., Macedo, D.S., Sales, P., Figueiredo, S.M., Daher, E.F., Araujo, S.M. . . . Carvalho, A.F. (2012). The relationship between religious coping, psychological distress, and quality of life in hemodialysis patients. *Journal of Psychosomatic Research, 72*, 129–135. doi:10.1016/j.jpsychores.2011.11.012

Sachs, O. (1998). *The man who mistook his wife for a hat*. New York, NY: Simon & Shuster, Inc.

Seeman, T.E., Dubin, L.F., & Seeman, M. (2003). Religiosity/spirituality and health. A critical review of the evidence for biological pathways. *American Psychologist, 58*(1), 53–63. doi:10.1037/0003-066X.58.1.53

Shamy, E. (2003). *A guide to the spiritual dimension of care for people with Alzheimer's disease and related dementia: More than a body, brain, and breath*. London, England: Jessica Kingsley.

Sherman, A.C., Simonton, S., Adams, D.C., Latif, U., Plante, T.G., Burns, S.K., & Poling, T. (2001). Measuring religious faith in cancer patients: Reliability and construct validity of the Santa Clara strength of religious faith questionnaire. *Psycho-Oncology, 10*(5), 436–433. doi:10.1002/pon.523

Sloan, R.P., & Bagiella, E. (2002). Claims about religious involvement and health outcomes. *Annals of Behavioral Medicine, 24*(1), 14–21. doi:10.1207/S15324796ABM2401_03

Sloan, R.P., Bagiella, E., & Powell, T. (1999). Religion, spirituality, and medicine. *Lancet, 353*(9153), 664–667. doi:10.1016/S0140-6736(98)07376-0

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd Ed.). Thousand Oaks, CA: Sage Publications.

Thai, L.J., Grundman, M., and Klauber, M.R. (1988). Dementia: Characteristics of a referral population and factors associated with progression. *Neurology, 38*, 1083–1090. doi:10.1212/WNL.38.7.1083

Thuné-Boyle, I.C., Stygall, J., Keshtgar, M.R., Davidson, T.I., & Newman, S.P. (2011). Religious coping strategies in patients diagnosed with breast cancer in the UK. *Psycho-Oncology, 8*, 386–394. doi:10.1002/pon.1784

Van Ness, P.H., & Kasl, S.V. (2003). Religion and cognitive dysfunction in an elderly cohort. *Journal of Gerontology: Psychological Science and Social Science, 58*(1), S21–S29. doi:10.1093/geronb/58.1.S21

Wimo, A., & Prince, M. (2010). *World Alzheimer's report 2010*. Retrieved from http://preview.alz.org/documents/national/World_Alzheimer_Report_2010.pdf

Yesavage, J.A., Brink, T.L., Rose, T.L., Lunn, O., Huang, V., Adey, M., & Leirer, V.O. (1983). Development and validation of the Geriatric Depression Scale: A preliminary report. *Journal of Psychiatric Research, 17*(1), 37–49. doi:10.1016/0022-3956(82)90033-4

 ISBN 978-90-04-25205-9