

West J Nurs Res. Author manuscript; available in PMC 2011 April 19.

Published in final edited form as:

West J Nurs Res. 2009 August; 31(5): 583–598. doi:10.1177/0193945909332776.

Using Spirituality to Cope with Early Stage Alzheimer's disease

Linda Beuscher, PhD, APN, BC[Assistant Professor] and

Vanderbilt University School of Nursing 461 21st Avenue South, Nashville, Tennessee 37240-1119, Phone: (615) 343-1849, Fax: (615) 343-7788 Linda.m.beuscher@vanderbilt.edu

Victoria T. Grando, PhD, APRN, BC[Associate Professor]
Arizona State University

Abstract

Alzheimer's disease (AD) robs persons living with this disease of their independence and self-esteem, which can lead to depression, anxiety, and loneliness. Understanding how people with early stage AD cope is a critical step to enhance their adaptive abilities and ultimately improve their quality of life. This qualitative study describes how individuals with early stage AD use spirituality to cope with the losses of self-esteem, independence, and social interaction that they face. The purposive sample for this focused ethnography study consisted of 15 participants living at home in central Arkansas. Holding onto faith, seeking reassurance and hope, and staying connected were the global themes. Personal faith, prayer, connection to church, and family support enhanced the ability for people with early stage AD to keep a positive attitude as they face living with Alzheimer's.

Keywords

Alzheimer's; spirituality; coping; qualitative

One hundred years have passed since Dr. Aloise Alzheimer first identified the characteristic neuropathology of a disease that bears Alzheimer's name. Now, Alzheimer's disease (AD) affects approximately 5.2 million people over 65 years of age in the United States (Alzheimer's Disease Education and Referral Center, 2008). Progressive losses of cognitive functions such as memory, problem solving, attention, language, and reasoning characterize the gradual irreversible degeneration of neurons (American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders [DSM-IV-TR], 2000). Significant psychological stress results as loss of cognitive function robs persons of their independence and self-esteem, which can lead to depression, anxiety, and loneliness (Katsuno, 2003; Matano, 2000). Moreover, as cognitive losses worsen, depressive symptoms may increase (Ross, Arnsberger, & Fox, 1998).

Despite advances in AD research, no prevention or cure exists. Enhancing older people's abilities to cope with the losses associated with AD should reduce some of their stress and be an important treatment goal (Jonas-Simpson & Mitchell, 2005). Indeed, assessing individuals' coping resources and helping them to cope effectively with their disease is a major nursing goal.

Coping with Alzheimer's

Alzheimer's disease affects an individual's thought process and memory and strains the ability to draw on coping skills and resources (Bahro, Silber, & Sunderland, 1995). Yet, research supports that individuals with early stage AD are aware of their cognitive impairment and are able to respond to their cognitive losses (Downs, 2005; Moore & Hollett, 2003). Those with AD are believed to develop compensatory coping strategies to maximize their sense of self-efficacy and psychological well-being (Clare, 2002). According to Clare, every individual has coping skills and resources derived from previous learning and experiences that influence how a person reacts to these cognitive losses. People with early stage AD actively attempt to adapt and cope with their memory loss, preserve their self-worth, and maintain a sense of normalcy. They compensate by relying on others, pursue ways to be useful, and focus on the good things in life (Clare, 2002; Macquarrie, 2005; Phinney, Wallhagen, & Sands, 2002).

Spirituality as a Coping Mechanism

Findings from numerous research studies indicate that spirituality is an important coping resource for older persons suffering from debilitating, chronic, severe, and terminal conditions. Furthermore, these studies reveal a beneficial association of spiritual coping to improved health and emotional well-being (Koenig, McCullough, & Larson, 2001; Narayanasamy, 2002). However, few studies have examined the role of spirituality to cope with early stage AD.

Spirituality is an intangible multidimensional concept that is challenging to define due to its subjective nature (Dyson, Cobb, & Forman, 1997). The concept of spirituality has been discussed by many disciplines; particularly nursing that embraces the holistic paradigm of body-mind-spirit. Although there is no consensus on the definition of spirituality, concept analyses generated by nursing scholars reveal common attributes such as belief systems, meaning and purpose of life, connectedness, and transcendence (Burkhardt, 1989; Delgado, 2005; Dyson et al., 1997; Emblen, 1992; Haase, Britt, Coward, Leidy, & Penn, 1992; Henery, 2003; McSherry, 2006; Merviglia, 1999; Newlin, Knafl, & Melkus, 2002; Tanyi, 2002). Currently, nursing scholars debate that modern nursing literature defines spirituality in a wider humanistic secular view than in the traditional context of religion (Paley, 2008; Pesut, 2008). According to Ross, (2008), this widening of the spirituality conceptual definition has occurred to meet patients' spiritual needs in our modern culturally diverse society. This position is also supported by qualitative research of nonreligious people who express spiritual feelings (Creel & Tillman, 2008). The underlying premises of the current study of people with AD are that all individuals are created as interrelated mind, body, and spirit. Therefore, each individual is uniquely spiritual and has spiritual needs.

Another issue is the lack of distinction between spirituality and religion. Koenig et al. (2001) offers this differentiation. Religion is an organized way to express spirituality such as prayer, meditation, and church attendance. It is community-focused, behavior oriented, and is only one component of spirituality. Spirituality is individualistic, emotional oriented and inward directed.

The present body of knowledge about spirituality in coping with the cognitive losses of early stage AD is derived from personal narratives of those personally coping with AD such as Davis (1989) and Taylor (2005) and six published research studies about quality of life for people with AD (Bahro, et al., 1995; Katsuno, 2003; Matano, 2000; Phinney, 1998; Snyder, 2003; Stuckey et al., 2002). These studies collectively reported that one third of the participants of older people with early stage AD suggested that their personal spirituality was important in their acceptance of losses, and relief from fears and anxiety (Beuscher &

Beck, 2008). In these six studies, individuals described spirituality as a faith or belief of a relationship with a greater being that provided meaning to suffering and purpose for life. In addition, one individual described spirituality in terms of her pragmatic approach to life and another person described spirituality as a connection with nature (Snyder, 2003). Being able to draw on one's spirituality to cope with AD was an element of perceived quality of life (Katsuno; Matano). Yet, there is a lack of in-depth information about how people with AD use their spirituality and what supports this process.

Research Questions

How do people with early stage AD use their spirituality to cope with their disease? What spiritual practices support this process? How has AD affected their spirituality or spiritual practices?

Method

An ethnographic approach was chosen to understand how individuals with AD cope within their own environment. Critical components of ethnographical research are interviews, observations, and field notes. Observations help confirm the analysis of the interview text. Observations of these individuals included the environment, the participants' language, nonverbal communication, and important artifacts or documents.

Sample

A purposive sample was recruited through referrals from the university-affiliated, Alzheimer Disease Center of a central Arkansas. Inclusion criteria included the following: (a) diagnosis of probable early stage AD according to the DSM-IV-TR, (b) score of 18-26 on the Mini-Mental State Exam, ([MMSE], Folstein, Folstein, & McHugh, 1975), reflecting early stage AD (Logsdon et al, 2002) (c) aged 65 years or older to capture the geriatric perspective, and d) able to provide consent or assent with written consent from their authorized representative. Any person with a diagnosis of schizophrenia or psychotic disorders was excluded from this study because of the delusional thinking and potential for associated religious fanaticism (Wilson, 1998). This sample consisted of 15 participants; predominately females (8), Caucasian (9), and married (8) with educational levels ranging from high school (3) to college education (12). Six African Americans represented the only ethnic diversity of the sample. Ages ranged from 67 to 91 years (M = 78.67; SD = 6.50). Participants either lived alone (5), with their spouse (8), or their adult children (2). Twelve participants could recall the number of years since being diagnosed with AD, which ranged from two to nine years (M = 4.37, SD = 2.29). This sample's mean MMSE score was 23.73 (SD = 1.98, range)21–26). All participants reported a Christian religious affiliation (3 Methodist, 4 Baptist, 3 Church of Christ, 2 Episcopalian, 2 Catholic, and 1 Lutheran), which was not surprising because Christianity is the predominate religion in this area of the south central United States. Sampling was terminated when data saturation was reached.

Data Collection

The University of Arkansas for Medical Sciences Institutional Review Board approval was obtained prior to conducting this research to ensure protection of participants' safety, rights, and dignity. Personnel from the Alzheimer Disease Center provided a referral list of potential participants, based on the inclusion criteria. The researcher then phoned potential participants to ascertain their interest in participating in this study and set up an initial meeting with them and their designated representative or family member. The initial meeting provided opportunity to establish rapport, answer questions about the study process, and obtain informed consent and assent. Individuals with cognitive impairment may not

have the capacity for consent but can give assent or verbal agreement to participate in a study. The researcher used the MacArthur Competence Assessment Tool for Clinical Research (Applebaum & Grisso, 2001) to determine capacity for consent. Family members' active involvement in the study was limited to the consent process, although at four interviews a family caregiver was present at the participant's request. This was acceptable to provide the participant psychological comfort and security. After consent and assent were obtained, the researcher conducted the MMSE as a screening tool to confirm inclusion criteria and then collected demographic information. Prior to each interview, the researcher spent 10 to 15 minutes in general conversation with the participant to build rapport and ease any apprehension. Semi-structured interviews were conducted in two sessions for 12 participants and three sessions for the other three participants. Multiple interviews with the same participant were conducted for additional observational time, fitting well with an ethnographic approach. This also established credibility and dependability of the data. The length of the interviews ranged from 20 minutes to 60 minutes depending on the participant's willingness and cognitive processing of questions. Following Lincoln and Guba's (1985) recommendations of establishing trustworthiness, the same researcher conducted all the interviews, using the same interview guide that was approved by two other experts in qualitative and dementia research. All interviews were tape-recorded for transcription. Data was collected until saturation was reached.

The interviews began with the grand tour question, how do you feel about having Alzheimer's disease? All participants were aware of their diagnosis of AD and in fact introduced the subject to the researcher during the introductory general conversations. Since it was critical to grasp understanding of the participants' definition of spirituality another important question was; what does spirituality mean to you? Other probe questions included: In what ways does Alzheimer's change your life? What helps you cope with these changes? What is the source of your hope and inner strengths? How has your spirituality changed because of Alzheimer's?

An observational instrument, developed by the researcher and finalized by use during the first three interview sites, facilitated consistent observation of the participants' home environment. These observations included items in their physical environment that illustrated expressions of spirituality, such as religious icons, reading materials, art, or pictures of family and friends. The researcher also observed the participants' nonverbal communication, movements and affect. Field notes of the researcher's observations were audiotaped immediately after the interviews, and then later transcribed verbatim from the audiotapes.

Data analysis

Data collection and analysis were performed concurrently. The interview data were transcribed verbatim and entered into the Ethnograph v5.0 computer software, which facilitated data management. First, the researcher read and reread the transcripts numerous times to become familiar with their content. Next, key concepts were identified from each transcribed data. A summary list of these key concepts formed the basis for coding data and later identifying factors and global themes. Codes were then entered into Ethnograph and coded texts were extracted and placed in individual codebooks. Using an iterative process of content analysis and constant comparison, texts were examined for content and compared to other texts for similarities and differences, leading to the development of common factors. The researcher triangulated the data from the interviews, observations, and field notes to provide contextual validity. Five factors that describe how spirituality was used in coping with AD were relying on God, praying, reading bible verses, belonging to church, and continuing church work. Based on similarities in meaning, these factors were combined into three themes: Holding onto personal faith, Seeking reassurance and hope, and Staying

connected. The factors and global themes were recorded with the supporting narrative description in individual codebooks, providing an audit trail (see Table 1). Coding was reviewed by another qualitative researcher to establish inter-rater reliability. Any discrepancies were discussed until consensus was met.

Results

Definition of Spirituality

Spirituality has multiple definitions in scholarly writings; however, all participants clearly defined spirituality within religious context as their belief and relationship with God. When asked what spirituality means to you, they spontaneously responded "the religious side of life", "thinking about God", "being part of church; it's a major part of my life". Spirituality was an important coping resource in other issues in their lives. Similar to others, (Hicks, 1999; McSherry, 2006) a definition of spirituality derived from this study is: Spirituality is an individual's belief developed through the lifespan that influences a person's interpretation of morals, faith, love, trust, suffering, and God. It guides a person's view of the world and self, providing structure, purpose, and meaning to everyday activities.

Holding onto Personal Faith

Relying on God—Participants positively described God as loving, caring, protecting, and providing. Furthermore, their belief in God provided a means to find acceptance of having AD, relief from worry, and hope in their life. For instance, one 77-year-old man quietly and willingly accepted his inevitable destiny with AD. He stated, "I figure if the Lord wanted me to have it, that's what is gonna happen. I just don't worry about it". Another man spoke metaphorically about how relying on God during troubled times throughout his life experiences was like using a crutch.

Your spirituality is always there to rescue you, but it requires letting the Lord be in your life. The world says it is a crutch. Okay, what is wrong with that. You got a broken leg; you welcome a crutch because it relieves the pain. Well, Christ is my crutch. He is there to lift me up and walk with me. That is a very strong comfort for me.

Observations of the participants' homes revealed symbols of their relationships or religious artifacts, such as crucifixes, crosses, angels, framed pictures with bible scriptures, and church hymnals. The consistency of interview data with observations strengthened the credibility of this factor and theme.

Seeking Reassurance and Hope

Praying—Daily appeals to God through prayer were important to 13 participants. These participants learned to use prayer during their childhood and early development of faith. Prayers were said before meals or at bedtime, a practice that continued in their adulthood. Furthermore, prayer was comforting and gave hope to these participants. For example, one woman shared "I pray every night and I always feel better after I do that. It gives me hope... I realize He knows what's best for me". Five participants stated that they specifically prayed for help dealing with their memory loss, "I pray at night when I go to bed and in the morning. I pray to be alert and to see another day". Four participants reported that they specifically prayed for their family caregivers.

Reading Bible verses—Reading, reciting or hearing certain bible verses were reassuring and comforting for all participants. For example, a 75-year-old man stated that saying bible verses "makes me feel good inside all the time". Specific meaningful bible verses reported by seven participants were: "Lo, I am with you always"; Psalm 23," The Lord is my

shepherd..." and John 3:16, "For God so loved the world..." One 72-year-old man described AD as a disease that affects you physically and emotionally. For him, the emotional aspect was the hardest to accept. When asked if there was a bible verse that was meaningful to help him cope with AD, teary eyed he replied, "Jesus wept'. That verse helps me, because if Jesus wept, then it's okay for me to be emotional."

These participants showed the interviewer their personal bibles and devotional prayer books and indeed these verses were bookmarked. Framed printed copies of Psalm 23 and John 3:16 hung in two homes, which the participants pointed out when talking about important scriptures.

Staying Connected

Belonging to church—Belonging to church provided identity, linked people to their past and provided an avenue for them to still be useful and have a purpose. "I've been involved in the church all my life. It's just a part of me". Twelve participants still attend their church or a group bible study. Social support and the fellowship with other members were the most frequently mentioned reasons that participants enjoyed attending church. One woman, who no longer attended church, missed that social support and felt lonely. She stated, "I felt different in church and I miss it ... the people, the hymns and the songs, shaking hands and social things at church ... I would be a more peaceable person if I were in church." Rituals, such as communion service were important to those three participants of Episcopalian and Catholic faiths. Five participants commented that they found comfort in the music hymns such as *Amazing Grace, My Faith Looks Up to Thee*, and *What A Friend We Have in Jesus*. Music also provided a connection to God. One lady stated, "Singing just made you feel happy knowing that God was there with you."

Continuing church work—Eight participants continue to serve in a church role such as deacons, choir member, and ushers or are involved in church ministries such as the food pantry. These activities fulfilled their needs to be useful and gave them a sense of accomplishment. The following quotes by three participants exemplify this point: "We help around the church, anything they need.... I keep doing and I don't want to stop"; "When [people at church] they got questions, they call on me for support".

Effect of Alzheimer's Disease on Spirituality

Fourteen participants said the cognitive losses did not affect their spirituality or beliefs. For these participants, their beliefs and relationships with God began during their childhood, continued to develop throughout life experiences, and continue to sustain them now in coping with AD. For example, an 84-year-old woman reflected:

The Lord helps me get through this. I don't dwell on sitting around worrying and all that kind of stuff because God has been good to me. He brought me from a long ways. Definitely, my faith is the power of my life.

This man later explained that the experience of having AD gave him a heightened spiritual sense. "My religion has always been a part of me and it gets stronger and stronger. It has gotten more intense."

Effects on spiritual practices—Since their cognitive impairment kept them from driving, transportation to church and church activities was important. One person relied on church to provide transportation to services. Another reported that she now watched church on the television. Families were the pivotal support for all 15 participants. Ten participants relied on their family members for transportation to church and church activities. They also depended on their families to remind them of church role-related meetings and activities.

The symptoms of AD also affected spiritual practices. Some individuals found that the symptoms of the disease (short attention span, declining reading comprehension and memory loss) interfered with their ability to engage in spiritual practices. Others found a renewed focus in what was most meaningful in their lives. Three participants no longer enjoyed listening to church sermons because they could not follow what the pastor was teaching. Only one man stated he no longer prayed because "I just get lost and forget what I'm doing, I guess." Loss of reading comprehension caused reading the bible to become such a frustrating task for four participants that they no longer read the bible. These four participants also had the lowest MMSE scores of the sample, which correlates with the expected progression of cognitive decline. The following statement by a 75-year-old man encapsulated the feelings of these four participants:

You've done read one thing [sic] and then you don't know what you are reading. It makes sense but it doesn't make sense to me when you think you are reading one thing and then it skips to something else.

One of these four participants overcame this obstacle. "I came up with the idea of putting a small ruler with a black edge on the page to read down from line to line so my eyes wouldn't fall off the sentences."

Some participants forgot bible verses that they memorized in their earlier years. A 67-year-old woman could not remember the words to Psalm 23, her favorite verse. However, when the researcher prompted her with the first two lines of the scripture, she was able to say the remaining verses by herself. She was surprised and proud that she could still recall the verses. This is an important finding because it provides an example of a simple intervention to help people with AD connect to a meaningful memory.

Discussion

The results add to the body of knowledge in several ways. First, the participants' lifelong faiths and the spiritual practices that they developed through their life experiences continue to exist despite their cognitive impairments. In addition, the participants reported that faith and spiritual practices helped them to find hope and acceptance of their cognitive losses, agreeing with findings from previous studies (Katsuno, 2003; Matano, 2000; Snyder, 2003; Stuckey et al, 2002). These findings highlight the impact that individuals' spirituality has on their ability to cope with AD. Furthermore, although the literature suggests that AD causes significant psychological stress, depression, anxiety, and loneliness (Katsuno, 2003; Matano 2000; Ross et al, 1998), these participants were positive and enjoying life day by day, which they attributed to their faith and their church and family support.

Second, spiritual practices were meaningful activities to connect with their personal faith, important memories, and present support. Prayer was the most important spiritual practice used for coping by this sample of participants. Prayer provided a personal connection with God and seemed to produce beneficial effects of emotional healing, reassurance, and hope (Narayanasamy & Narayanasamy, 2008). This finding is similar to the research literature about elders coping with chronic and disabling illness (Koenig et al., 2001). It also lends support to Post's (2000) conjecture that prayer is important to persons with AD because it provides a sense of control over the progressive cognitive impairment.

The word prayer comes from the Latin *Precari*, 'to entreat', or ask earnestly. It comes from the same root as the word *precarious* and it is in the precariousness of emerging forgetfulness that often drives the person with dementia to prayer. (p.137)

Another important spiritual practice used for coping was engagement in church activities, which provided vital connections with other people and possibly a sense of belonging and

identity for the individual with AD. Since AD interferes with verbal communication and comprehension of conversations, individuals with AD often become socially isolated. In addition, losing one's memory also means losing one's self-identity. Being a member of a faith community is an identity; therefore, may provide a sense of belonging and offer opportunities to break the social isolation. In fact, five participants used the term "belong to" church or choir. Interestingly, the two participants in this study who spoke of feeling isolated also no longer attended the churches that they had attended for many years. Notably over half of the study participants continued to serve in church roles fulfilling their need to be useful and productive, differing from Snyder's (2003) participants who reported decreased attendance. In addition, it suggests that in some faith communities, individuals with AD may be more accepted and supported. These examples emphasize the significance of the social network within church memberships (Swinton, 2000).

Third, this study adds to the body of knowledge of African Americans coping with AD, who have been historically under-represented in Alzheimer's research. This sample of African Americans turned to their religion and prayer as primary coping resources when confronted with the life changes from AD. This finding is consistent with nursing literature that spirituality and religious coping with other health problems are a prominent component of the lives of African Americans (Banks-Wallace & Parks, 2004; Ferraro & Koch, 1994; Newlin et al., 2002). These findings merit further research with diverse ethnic participants, since AD affects people across ethnic cultures. Full details of these findings were not discussed here, but will be the topic of another article.

Fourth, these findings provide insight of how AD affects individuals' spiritual practices. Not surprising was the decrease in reading scriptures due to loss of reading comprehension. Perhaps audio bibles would be beneficial, although only one participant reported trying that option.

A limitation of this study is the small homogenous sample obtained from an Alzheimer Disease Center research database. Older individuals who agreed to participate in this study may have different characteristics or personalities than the general population. For example, 12 participants (80%) in this sample had some college education and therefore may have a different viewpoint of spirituality and diverse coping resources. This sample also did not include people younger than 65 with early onset AD. Furthermore, since the focus of this study was spirituality in coping, some people may have agreed to participate in this study because of their strong motivation and interest in spirituality. Others may have refused to participate because of negative feelings about their faith, e.g. blame God for their disease. Four individuals did not wish to participate in the study, expressing that they were "already involved in another study" or "too ill to talk". All the participants defined spirituality within a religious context and indeed reported an affiliation to Christian religions, which is representative of elders living in the southern United States. Therefore, this study lacks representation of other beliefs who may define spirituality differently. These limitations should compel researchers to conduct studies with people of other beliefs and in other geographical areas of the United States.

Results from this study reinforce that people with early stage AD utilize effective coping resources such as personal spirituality. Future longitudinal studies might lead to an understanding of how AD affects individuals' spirituality to cope as their cognitive impairment progresses. In addition, future studies might include the caregiver's perspective to enrich the findings. Since people younger than 65 have been diagnosed with AD, they should be included in future studies. Finally, the body of knowledge needs to move forward from descriptive studies to tailored intervention studies that can translate to care outcomes for those with AD.

Spirituality and coping skills are unique to each individual. Therefore, interventions that are more effective may be those tailored to spiritual coping skills that individuals developed before the cognitive impairment worsened. The findings from this study suggest a few potential tailored interventions for future research. For example, providing simple auditory or visual cues may trigger memories of meaningful and comforting scriptures or rituals and thus decrease anxiety or agitation. Familiar meaningful music such as older hymns may also be effective to decrease agitation. Assistance with bedtime prayer may be calming and improve sleep for people who routinely said prayers at bedtime. Repeating a simple prayer or just folding of praying hands before meals may improve eating and thus reduce undesirable weight loss for those who used this spiritual practice in the past.

Findings from this study bear important implications for clinical practice to nurses and the multidisciplinary professionals who will interact with individuals with AD sometime during the course of diagnosis and management of the disease. Spirituality was an important resource for coping in this research sample of people with early stage AD and the six previously published studies. This emphasizes the need to acknowledge and respect the individual's spiritual beliefs and to include a spiritual history in a comprehensive assessment of coping responses and resources. A spiritual history is imperative for understanding the value of faith traditions and rituals to their patients. Several coping and spiritual coping assessment tools are available that may identify appropriate and inappropriate coping responses. Koenig's book, *Spirituality in Patient Care* (2002) provides a comprehensive list of spiritual history assessment tools that are patient-centered and easy for clinicians to use. If an assessment identifies spiritual need then referrals to chaplains or pastoral care should be made.

Important opportunities exist for nurses to educate faith communities about the disease process and ways to support those with AD. Particularly, the results of this study will be useful to parish nurses, a nursing specialty, who provide health and spiritual care to people with AD within faith communities (Tuck, Wallace & Pullen, 2001). An excellent educational resource is the book; "You are one of us, Successful clergy/church connections to Alzheimer's families" (Gwyther, 1995).

There is also opportunity to educate caregivers about the significance of spirituality for coping with AD (Narayanasamy, 2004). This information will provide caregivers with knowledge of how to work with people afflicted with AD, to maximize those individuals' coping potentials and maintain their dignity. However, nurses must also teach caregivers to avoid introducing or imposing religious values, beliefs or practices on people with AD because caregivers feel it is in the patient's best interest. This was a concern voiced by Taylor (2005) who was diagnosed with AD. Taylor wrote that if religion and religious practices were important to the person with AD in their personal life history, then that aspect of their life should be respected and allowed to continue. However, if it was not a focus in their life, then there is no reason to think that it will become important.

In conclusion, there are individuals with early stage AD cope with the losses of self-esteem, independence, and social interactions by drawing on their faith and spiritual activities to find comfort, security, a sense of belonging, and identity. Understanding how people use spirituality to cope is a critical step to developing tailored interventions to enhance their adaptive abilities and ultimately improve their quality of life.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

This study was funded by the John A. Hartford Building Academic Geriatric Nursing Capacity Scholarship Program and Beverly Enterprises. Authors acknowledge support from the University of Arkansas for Medical Sciences Alzheimer's Disease Center (National Institute of Health, National Institute on Aging, Grant P30 AG19606).

References

- Alzheimer's Association. 2008 Alzheimer's Disease Facts and Figures. 2008 [Retrieved May 3, 2008]. from http://www.alz.org/alzheimer's_disease_publications_reports.asp
- American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 4th ed.. Washington DC: Author; 2000.
- Applebaum, PS.; Grisso, T. MacArthur competence assessment tool for clinical research. Sarasota, FL: Professional Resource; 2001.
- Bahro M, Silber E, Sunderland T. How do patients with Alzheimer's disease cope with their illness? a clinical experience report. Journal of the American Geriatric Society. 1995; 43(1):41–46.
- Banks-Wallace J, Parks L. It's all sacred: African American women's perspectives on spirituality. Issues in Mental Health Nursing. 2004; 25:25–45. [PubMed: 14660315]
- Beuscher L, Beck C. Exploring spirituality in coping with early stage Alzheimer's disease: A literature review. Journal of Nursing and Healthcare of Chronic Illness, in association with Journal of Clinical Nursing. 2008; 17(5A):88–97.
- Burkhardt MA. Spirituality: An analysis of the concept. Holistic Nursing Practice. 1989; 3(3):69–77. [PubMed: 2670980]
- Clare. We'll fight it as long as we can: Coping with the onset of Alzheimer's. Aging & Mental Health. 2002; 6(2):139–148. [PubMed: 12028882]
- Creel E, Tillman K. The meaning of spirituality among nonreligious persons with chronic illness. Holistic Nursing Practice. 2008; 22(6):303–309. [PubMed: 18981809]
- Davis, R. My journey into Alzheimer's disease. Wheaton, IL: Tyndale House; 1989.
- Delgado C. A discussion of the concept of spirituality. Nursing Science Quarterly. 2005; 18(2):157–162. [PubMed: 15802748]
- Downs M. Awareness in dementia: In the eye of the beholder. Aging & Mental Health. 2005; 9(5): 381–383. [PubMed: 16024396]
- Dyson J, Cobb M, Forman D. The meaning of spirituality: A literature review. Journal of Advanced Nursing. 1997; 26(6):1183–1188. [PubMed: 9429969]
- Emblen JD. Religion and spirituality defined according to current use in nursing literature. Journal of Professional Nursing. 1992; 8(1):41–47. [PubMed: 1573115]
- Ferraro K, Koch J. Religion and health among black and white adults: Examining social support and consolation. Journal of Scientific Study of Religion. 1994; 4:362–375.
- Folstein M, Folstein S, McHugh P. Mini-mental state: A practical method grading the cognitive state of patients for the clinician. Journal of Psychiatric Research. 1975; 12:189–198. [PubMed: 1202204]
- Gwyther, LP. You are one of us. Successful clergy/church connections to Alzheimer's families. Durham, NC: Duke University Medical Center; 1995.
- Haase JE, Britt T, Coward DD, Leidy NK, Penn PE. Simultaneous concept analysis of spiritual perspective, hope, acceptance, and self-transcendence. Image: Journal of Nursing Scholarship. 1992; 24(2):141–147.
- Henery N. Constructions of spirituality in contemporary nursing theory. Journal of Advanced Nursing. 2003; 42(6):550–557. [PubMed: 12787228]
- Hicks TJ. Spirituality and the elderly: Nursing implications with nursing home residents. Geriatric Nursing. 1999; 20(3):144–146. [PubMed: 10661104]
- Jonas-Simpson C, Mitchell GJ. Giving voice to expressions of quality of life for persons living with dementia through story, music, and art. Alzheimer's Care Quarterly. 2005; 6(1):52–61.
- Katsuno T. Personal spirituality of persons with early stage dementia. Dementia. 2003; 2(3):315-335.

Koenig, HG. Spirituality in patient care: Why, how, when, and what. Philadelphia, PA: Templeton Foundation Press; 2002.

- Koenig, HG.; McCullough, ME.; Larson, DB. Handbook of religion and health. New York: Oxford University Press; 2001.
- Lincoln, ES.; Guba, EG. Naturalistic inquiry. Beverly Hills, CA: Sage; 1985.
- Logsdon RG, Gibbons LE, McCurry SM, Teri L. Assessing quality of life in older adults with cognitive impairment. Psychosomatic Medicine. 2002; 64(3):510–519. [PubMed: 12021425]
- Macquarrie CR. Experiences in early stage Alzheimer's disease: Understanding the paradox of acceptance and denial. Aging & Mental Health. 2005; 9(5):430–441. [PubMed: 16024402]
- Matano, T. Unpublished doctoral dissertation. Chicago, IL: University of Illinois at Chicago; 2000. Quality of life of persons with Alzheimer's disease.
- McSherry W. The principal components model: A model for advancing spirituality and spirtual care within nursing and health care practice. Journal of Clinical Nursing. 2006; 15:905–917. [PubMed: 16879383]
- Merviglia MG. Critical analysis of spirituality and its empirical indicators: Prayer and meaning in life. Journal of Holistic Nursing. 1999; 17:18–33. [PubMed: 10373840]
- Moore T, Hollett J. Giving voice to persons living with dementia: The researcher's opportunities and challenges. Nursing Science Quarterly. 2003; 16:164–167.
- Narayanasamy A. Spiritual coping mechanisms in chronically ill patients. British Journal of Nursing. 2002; 11(22):1461–1470. [PubMed: 12514485]
- Narayanasamy A. The puzzle of spirituality for nursing: a guide to practical assessment. British Journal of Nursing. 2004; 13:1140–1144. [PubMed: 15573007]
- Narayanasamy A, Narayanasamy M. The healing power of prayer and its implication for nursing. British Journal of Nursing. 2008; 17(6):394–398. [PubMed: 18414311]
- Newlin K, Knafl K, Melkus G. African-American spirituality: A concept analysis. Advances in Nursing Science. 2002; 25(2):57–70. [PubMed: 12484641]
- Paley J. Spirituality and nursing: A reductionist approach. Nursing Philosophy. 2008; 9(1):3–8. [PubMed: 18154633]
- Pesut B. A conversation on diverse perspectives of spirituality in nursing literature. Nursing philosophy. 2008; 9(2):98–109. [PubMed: 18336707]
- Phinney A. Living with dementia from the patient's perspective. Journal of Gerontological Nursing. 1998; 24(6):8–15. [PubMed: 9709064]
- Phinney A, Wallhagen M, Sands LP. Exploring the meaning of symptom awareness and unawareness in dementia. Journal of Neuroscience Nursing. 2002; 34(2):79–90.
- Post, SG. The moral challenge of Alzheimer disease ethical issues from diagnosis to dying. 2nd ed.. Baltimore: Johns Hopkins University Press; 2000.
- Ross L. Commentary on Paley J spirituality and secularization: Nursing and the sociology of religion. Journal of Clinical Nursing. 2008; 17(20):2795–2798. [PubMed: 18808651]
- Ross LK, Arnsberger P, Fox PJ. The relationship between cognitive functioning and disease severity with depression in dementia of the Alzheimer's type. Aging & Mental Health. 1998; 2(4):319–327.
- Snyder L. Satisfactions and challenges in spiritual faith and practice for persons with dementia. Dementia. 2003; 2(3):299–313.
- Stuckey JC, Post SG, Ollerton S, FallCreek SJ, Whitehouse PJ. Alzheimer's disease, religion, and the ethics of respect for spirituality a community dialogue. Alzheimer's Care Quarterly. 2002; 3(3): 199–207.
- Swinton, J. Resurrecting the person; Friendship and the care of people with mental health problems. Nashville: Abington Press; 2000.
- Tanyi RA. Towards clarification of the meaning of spirituality. Journal of Advanced Nursing. 2002; 39(5):500–509. [PubMed: 12175360]
- Tuck I, Wallace D, Pullen L. Spirituality and spiritual care provided by parish Nurses. Western Journal of Nursing Research. 2001; 23(5):441–453. [PubMed: 11482050]

Taylor R. Alzheimer's disease experienced: From the inside out. Alzheimer's Care Quarterly. 2005; 6(4):265-272.