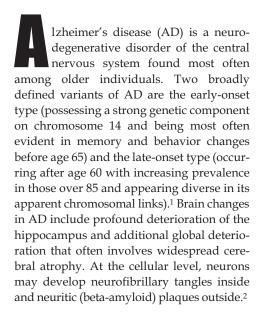


An Individualized Approach to Religious Coping in Alzheimer's Disease

Lauren S. Seifert and Melinda K. Baker

Previous research has indicated the importance of religious coping among caregivers of individuals with dementia. However, there is almost no empirical research about religious coping among individuals with dementia. It is difficult to measure religious coping directly since many obstacles to improve coping strategies, particularly in diseases like probable Alzheimer's, prevent the uses of conventional measures of coping and of traditional therapies for improving one's positive coping strategies. Additional problems may be co-morbidity with serious physical ailments and adapting psychotherapeutic interventions to include religious coping and to suit individuals with progressive cognitive decline. We propose a practical approach to the topic and recount case evidence.



Early in the course of the disease, individuals have difficulty finding words (such as names of objects, in otherwise fluent speech), forget recent events and conversations, and exhibit changes in personality with episodes of confusion and disorientation (e.g., to time or place). As AD progresses, individuals exhibit perseveration of familiar behaviors (like preparing to make a meal or asking when the bus will arrive); lose the ability to track time, activities, and conversations; and eventually lose the abilities to

perform even well-learned tasks like grooming, feeding, and toileting.

AD is the most common cause of dementia among elderly individuals, and there is no known cure. The best current treatments tend to work early in the course of the disease with effectiveness of key medications declining in the later stages (Stages 5, 6, 7: when AD patients' memories, problem solving, attention, and overall health decline).3 Barry Reisberg and his colleagues have described decline from AD as seven stages of "global deterioration" from Stage 1 (no cognitive deficit) to Stage 7 (profound cognitive deficit).4 AD becomes noticeable and is usually diagnosed as a person experiences growing forgetfulness and anomia (difficulty with word finding, usually in Stages 2 and 3). Eventually, functioning deteriorates through phases of increasing confusion, lost orientation to time and place, and lost verbal skills-and then to end-stage dementia in



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Alzheimer's disease (AD) is a neuro-degenerative disorder of the central nervous system found most often among older individuals.

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which the person does not speak, locomote, toilet, groom, or feed.⁵

Since the industrial revolution in Westernized nations, dementia care has followed a path similar to that of general "aging care": to institutionalize the very ill in order to maintain stability in the larger, industryfocused society and to create a "total institution" in long-term/nursing-home care settings that focuses on routine and regulation. Many are the families who have been dismayed at the regimentation and inflexibility of long-term care. Dismay among baby boomers, who are also the adult children of aging parents, is catalyzing slow reform. These adults are rediscovering the advantage of individualized care, because it focuses on the value of one's aging parent rather than diminishing him or her to "livestock status" with mere requirements for feeding, bathing, and toileting.

Titles of recently written guides on caregiving in dementia reflect sentiments of reform. In dementia care that is "personcentered," care planning no longer accentuates differences across "sectors" of care (e.g., medical versus mental health versus pastoral versus rehabilitative). Instead, dementia care is refocused on the "whole person" and on meeting the individual's needs by integrating care across many professions. Teams comprised of many different types of professionals can work together to provide integrated, whole-person care.⁶

In his article on dementia and faith, Malcolm Goldsmith observed: "To provide imaginative care of the highest quality is a daunting task. It is often lonely and it often seems as if we go two steps backward for every one step forward." In our views, person-centered care uplifts the person from "livestock" to "lovestock" with an emphasis on the value of each individual (e.g., as can be witnessed in many of the techniques for dementia care that have originated in Sweden during the past two decades). Several er B.A. in Psychology from Malone College where with Dr. Lauren Seifert. She completed a



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passages of Scripture direct that type of uplifting behavior, including Matt. 19:19b (NIV) "... love your neighbor as yourself" and—as Goldsmith also has noted—the mandate in 1 Cor. 12:22–23 (NIV): "On the contrary, those parts of the body that seem to be weaker are indispensable, and the parts that we think are less honorable we treat with special honor."

In his chapter arguing that dualism is unneeded as a crutch to justify human worth, Stephen Post contended that the equal worth of each human is wholly justified by Christ's example of agape. He stated:

... the image of Christ's love properly appreciated will hopefully permeate any anthropology with the power of its insistence on radical inclusivity ... It is the story of Christianity that strongly demands solicitude for all, including those with retardation and dementia.¹⁰

Goldsmith argued that there are ways in which the petulant and transient worlds of faith and dementia can interact. However, he also stated that those interactions must be person-centered and that faith-based approaches to life must be made accessible to the individual with dementia, e.g., through uplifting love from a community of faith.¹¹

A further caution from Elizabeth MacKinlay is that spiritual or faith hunger should not be mistaken as mere psychosocial need.¹² She stated that techniques for satisfying the latter will leave the former desires unmet. In her study to evaluate outcomes of a workshop for improving nurses' awareness of their patients' spiritual needs, MacKinlay stressed the importance of evaluating and attending to both the broadlybased yearnings that evolve from shared humanness and the specific spiritual needs that derive from an individual's understanding of life's meaning and his or her place therein.¹³ Thus she has indicated the critical nature - in considerations of dementia and dementia care - of the search for that which is sacred, of the search for life's meaning in ways associated with the sacred, and of ideas about coping that are primarily religious in nature. 14 Without discussions of religious coping, i.e., ways of coping that relate beliefs and behaviors to the sacred, debates about dementia care and coping with AD are incomplete.¹⁵

There exists an extensive literature in psychology about coping such as how individuals assess their environment, relationships, and selves; and how individuals respond to perceived threats and perceived supports. ¹⁶ In this article, our goal is not to recapitulate the vast literature on personality, stress, and coping. Neither is it our goal to review the literature on religious coping in adulthood and aging. ¹⁷ Instead, our goal is to speak directly to the need for further consideration of religious coping in dementia and dementia care.

Assessing Spiritual Needs in Dementia

Harold Koenig has described a critical need in gerontology (an interdisciplinary field that includes medical practitioners, mental health care professionals, rehabilitation specialists, research scientists, clergy and many more) for research on religious coping by individuals with Alzheimer-type dementia (DAT; i.e., the type of dementia that occurs in AD) and associated types of dementia. 18 Surprisingly, there is very little empirical work on the topic, and most pertinent articles are either about larger projects in which the study of religious coping in dementia was tangential to the main purpose or in which conclusions were based on non-empirical observations.¹⁹ General research on aging suggests that a person's religiousness and spirituality remain stable during adulthood.²⁰ Attitudes about the sacred and about religion do not seem to change, even when there are impediments to church attendance.²¹ However, researchers have not studied dementia's effects on an individual's attitudes about religion and his or her religious behaviors. How do those attitudes and behaviors change when a person experiences cognitive decline due to AD?

One great difficulty in dementia research (i.e., in psychology and sociology) has been the measurement of religious coping, because most measures are self-report and involve sensitive questions about one's coping strategies, e.g., the Religious Coping Index.²² For individuals with dementia who may feel anguish associated with knowledge about their diagnosis, questions about coping with the disease can be disconcerting. Indeed, it is not uncommon for them to verbalize a sense of hopelessness.²³ Moreover, for mid- and late-stage patients, items on a religious coping questionnaire may be difficult to comprehend or difficult to answer with self-report. Consistent with that notion, Koenig and his colleagues reported data on religious coping only for those research participants with initial scores on the Mini-Mental State Exam (MMSE) above 14, presumably because religious coping was difficult to measure in lower-functioning patients (as is true of many measures that utilize self-report and which heavily rely upon verbal skills).24

Ethical guidelines in medicine, psychology, and social work (and in similar health care professions which have

ethics codes for licensed practitioners) caution a practitioner against causing harm, e.g., the Hippocratic Oath in medicine and the APA "Ethical Principles of Psychologists and Code of Conduct."25 When one considers the additional issue of disorientation or confusion, asking for selfreport about coping may seem inappropriate when the patient has moderate-to-severe AD. Although it is unlikely that a simple query about one's coping strategies might cause lasting harm, questions that require more reflection about the nature of his or her mortality and disease must be weighed against a person's ability to process the meanings of such issues. A practitioner must evaluate whether a client is capable of responding to such questions, and whether the progression of the disease might interfere with attempts to teach him or her new, more positive coping strategies.

A practitioner must evaluate whether a client is capable of responding to [questions of mortality and AD], and whether the progression of the disease might interfere with attempts to teach him or her new, more positive coping strategies.

For medical practitioners and mental health care professionals who wish to assist patients and their families to cope with AD, some of the best approaches to assessment and assistance may be through family and friends.²⁶ A clinician or researcher with savvy will utilize converging techniques for gathering evidence, including collecting a detailed medical history, administering tests that measure cognitive skills (like the MMSE, Clock Drawing, BCRS),²⁷ assessing functional independence and skills (the ability to perform the activities of daily living [ADL's] and to perform physical tasks),²⁸ and interviewing primary caregivers to obtain key information about a client's level of functioning (using measures like the NPI and GAFS).²⁹ Additional measures for assessment of substance abuse, mood, and social support may be useful. 30 Finally, while there do exist measures for assessing spiritual support and religious coping, not all of them have been adapted for use with those who have AD.31 Assessing spiritual support and support for religious coping also should include: (1) the



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client's history and pre-morbid strategies for coping; (2) the accessibility of and types of social support; and (3) the availability of external memory support (e.g., in the physical environment and in the client's social network) for sustaining positive coping strategies.

Insights about Religious Coping in AD

Perhaps the most informative exposition on religious coping in AD is My Journey into Alzheimer's Disease by Reverend Doctor Robert Davis.³² He described the fear and anxiety that seemed to replace his feeling of closeness to God. With his wife's help, he wrote about his awareness of this loss of closeness. Davis recounted the emotional pain of his deteriorating memories of favorite prayers and Scripture passages. Given Davis's report of his own experience, one can conjecture about the loss of ability to use religious coping among individuals with Alzheimer-type dementia. It seems clear that Davis utilized religious coping effectively in the years prior to his diagnosis with AD. His own account of post-morbid struggles to utilize religious coping indicates how very difficult the challenge can be-even for someone who had automatized many religious coping strategies pre-morbidly.33

As mentioned previously, a critical ethical issue for mental health professionals is determining whether it is appropriate to attempt to facilitate religious coping among individuals with AD. From a professional perspective (e.g., in psychology), such attempts might be contraindicated when: (1) assessment (as recommended above) yields no evidence of a pre-morbid preference for religious coping; (2) an individual with AD shows no interest in religious coping; and (3) there is no consent from an individual's legal guardian (as is required when one studies and/or treats an individual who cannot give his or her own consent; e.g., local, state, and federal laws governing research and practice; see also the APA Ethics Code).³⁴

William Clements argued that "spiritual development comes from identity and identity requires memory." If so, then one should not prevail upon a person with AD to "develop" spiritually. Instead, effective religious coping in AD most likely will depend

upon a behavioral framework that was learned before significant cognitive decline occurred.

The foregoing conceptualization is consistent with Davis's opinion.36 Davis rebuked himself for begging individuals with dementia to repent and hear God when he was a young minister. Later in his life, as he sensed his own cognitive decline due to AD, he realized that imploring someone to listen and repent is more likely to confuse and cause anguish than to effect a new connection with God. Davis suggested gentle touch and softly spoken words as spiritual support for individuals with dementia. He contended that those behaviors might communicate the love of God to such a person better than appeals to repent.³⁷ A patient's level of dysfunction related to AD (mild, moderate, or severe³⁸) would be just one of many considerations in determining whether interventions related to religious coping are at all appropriate in a specific case. (See the aforementioned suggestions for determining the appropriateness of supports for religious coping, which should include proper assessment across several sources of evidence.)

"Making the Case" for Religious Coping in AD

It has been observed that caregivers of individuals with a chronic illness experience better adaptations when they (self-)report stronger internal religiosity.³⁹ This also might be true for individuals with AD for whom higher internal religiosity could be associated with more positive coping outcomes. [Note our assumption that religious coping and internal religiosity should be positively correlated, despite a few situations in which they might not be.] Unfortunately, the vast literature on AD addresses many aspects of cognitive and perceptual-motor decline without specifically assessing spiritual changes.⁴⁰ If religiousness and religious coping strategies could lead to positive coping outcomes in AD, then how might family, friends, mental healthcare providers, and medical professionals foster its occurrence? And why might one even believe that religious coping is possible when a person has AD?

Positive religious coping might best suit those who have employed it pre-morbidly, because procedural skills for maintaining

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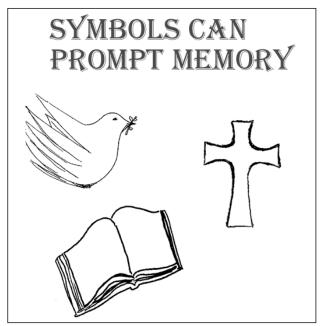
occurred.

well-practiced behaviors (like an individual's specific behavior patterns or approaches to coping) often remain intact for some period of time after disease onset.⁴¹ In a landmark study, David Knopman and Mary Jo Nissen observed that a patient might be able to carry out a procedure, like getting dressed, well into the course of AD, without also being able to explain or explicitly recall that procedure.42 One could argue that strategies for coping in adulthood are procedures that an individual automatizes over time through experience and practice. If those procedures do become automatized, then an individual with AD should be able to continue to utilize them during the early and middle stages of the disease when many implicit and procedural memories remain intact. Symbolic rituals and sacred objects of faith may serve to cue intact procedural memories, and Goldsmith has compiled a partial list of specific stimuli for cuing those types of memories such as lighting candles, singing or playing particular types of music, and wearing specific attire (e.g., clerical collar).⁴³ We suggest that following a specific liturgy or a planned order of events within worship might provide powerful memory cues for individuals with AD. Also, detailed histories about a person's religiosity, careful observations of post-morbid behaviors, and simple changes in his or her post-morbid environment may be the keys to facilitate religious coping among individuals with AD. They may provide powerful external cues that help one remember his or her coping strategies and "procedures."

Illustrative Cases

In our research that pertains primarily to memory change and procedural skills over the course of AD,⁴⁴ we have observed patients' behavior patterns over long intervals.⁴⁵ In some cases, there has been a conspicuous absence of religious objects that had been important to individuals before the apparent onset of probable AD. Often individuals with AD are moved out of their own homes and into long-term care for the purposes of helping them (and their family/caregivers) with the burdens of physical care and behavior management. In such moves, many important possessions are left behind, and those may include religious symbols (e.g., a cross, a crucifix, a family book of Scripture) that are important reminders of faith and of one's approach(es) to coping through faith and religion.

We have heard many caregivers of AD patients report anecdotes related to pre-morbidly learned methods of religious coping. In some cases, caregivers failed to understand the significance of religious coping in the life of the individual with AD and in so doing apparently catalyzed combativeness (e.g., taking a family Bible to give to a grandchild, and in so doing, removing an important memory cue for religious coping from the family member with AD—thus creating confusion and frustration that could not be adequately explained by the individual with AD). In other cases, caregivers recognized a need for a specific



Original drawings by Toby and Lauren Seifert

approach to religious coping and apparently were able to help the individual with dementia. The cases described below are examples of success in facilitating religious coping.

We suggest that following a specific liturgy or a planned order of events within worship might provide powerful memory cues for individuals with AD.

During early Autumn, a female resident (MMSE = 16; aged 81 years; with dementia of the Alzheimer's type diagnosed five years previously via clinical neuropsychological assessment) of a long-term care facility in Ohio presented with depression and general confusion when moved from her home of many years to the facility. Several breakable items were brought from her home and placed in a locked cabinet with a clear, shatter-resistant panel so that she could observe them without breaking them. The cabinet also reduced the risk that the items would be stolen. At least twice each week for three weeks, the resident would insist that her valuables be removed from the cabinet so that she could pack them and move back to her home. Frequencies of wandering and aggressive vocalizations were high, with incidents reported almost daily. At that time, little was known about her religious background.



In our research on memory change over the course of dementia, we have documented many situations in which a specific religious item or object holds significance for the individual

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Shortly before the Advent season (i.e., during November), it was learned that the resident identifies herself as "Catholic," and a caregiver observed that one of her "valuables" in the locked cabinet was a gold cross. On one occasion, when the resident asked to receive her belongings from the cabinet, she took special interest in the cross, specifically mentioned it, held it up, and then placed it in her purse. It was decided that she would keep it in her handbag, and the other items were returned to the cabinet. After that, she no longer asked about the items in the cabinet. She has kept the cross in her purse (as we observed over the course of three months) and has taken on the appearance of praying - with the cross held tightly against her chest. When one of us asked the resident about the cross, she smiled and took it out of her purse. Afterward, she was observed polishing it and holding it firmly. The frequency of incidents of combativeness associated with spontaneous verbalizations about the cabinet and its contents dropped to zero following the removal of the cross from the cabinet (and continued to be zero for three months following its removal from said cabinet - after which time we ceased to take measures on the behavior).

In the foregoing illustrative case, religious coping seems to have been impaired by the physical removal of a religious object from the individual with AD. With the item remaining in view (i.e., in the cabinet), the resident's memory of her own approach to religious coping was most likely cued. However, since she could not touch or handle the object, this may have been a source of frustration, because she seems to have relied on handling it as part of her approach to praying and coping with anxiety-producing situations. After the cross was returned to her possession, her frustration appeared to diminish (as indicated by the cessation of her attempts to remove the remaining items from the cabinet with the goal of packing to go home), and she was able to resume a previously learned approach to religious coping: handling the object as part of a regimen to reduce anxiety. Her family reports that prayer, with the cross in-hand, was a pre-morbid behavior.

Admittedly, there may have been additional factors that contributed to the decline in her combativeness—including the mere

passage of time, which may have facilitated her adjustment to the new residence. However, the relationship between her possession of the cross and her resumption of a behavior that appears to be prayer or spiritual reflection does seem to be strong. In the absence of the caregivers' comprehension of that relationship, the resident might have continued indefinitely to be combative and frustrated about the locked cabinet. Therein resides the value of the professional assessment: through an analysis of information about the history of the individual, this situation was brought to a useful and happy resolution.

In our research on memory change over the course of dementia, we have documented many situations in which a specific religious item or object holds significance for the individual with AD. The following cases are additional examples across several Christian denominations.

An article of clothing that was worn to church pre-morbidly (and only on the Sabbath) was used to orient a resident in long-term care (MMSE = 15; aged 92 years with diagnosis of Alzheimer-type dementia two years previously) to the day of the week. She was gently reminded to put it on in preparation for an afternoon visit from her minister. Thus, the clothing served dual purposes: orientation to day and orientation to upcoming fellowship with clergy.

Another individual in long-term, residential care (MMSE = 25; aged 70 years with diagnosis of Alzheimer-type dementia one year previously) who loves to sing hymns was able to derive spiritual support from clergy visits with an emphasis on music. In fact, she remembered his visits from weekto-week and often described the music they sang together.

A third individual also in residential, long-term care (MMSE = 16; aged 81 with diagnosis of Alzheimer-type dementia five years previously) enjoyed the Twenty-Third Psalm and recited it with assistance. She appeared to enjoy that help, and often thanked the assistant (the first author) for her help in recitation.

In all of these illustrative cases, the outcomes were favorable as they related to the utilization of religious symbols and/or activi-

with AD.

ties to enhance the quality of daily life and positive coping among individuals with AD. It is key that caregivers in each case focused on the needs and behaviors of the individual and on the behavior tendencies of that person, with careful analysis of the history of the individual and his or her current abilities and circumstances.

Conceptualizing Religious Symbols as Memory Cues

The aforementioned examples (and the many similar cases one encounters when working with individuals with AD) illustrate the need for a model of behavioral intervention that would facilitate religious coping among individuals with dementia. This model of "spiritual support intervention," as described above, would (1) reside within the ethical guidelines in one's discipline for care of individuals with dementia; (2) regard a person's tendency toward religious coping, his or her expressed interest in religious coping, and his or her legal guardian's wishes concerning this matter; (3) take into account several aspects of pre-morbid life (including personal history, church history, history of coping and social support); and (4) include a careful analysis of the client's current cognitive, social, emotional, and physical circumstances. Overall, these factors will help determine whether active spiritual support is feasible. 46

The foregoing cases provide preliminary evidence for roles of religious coping among individuals with AD and limited, but successful, spiritual support for those individuals. Critical ethical issues about when supports are feasible and appropriate must be left to the assessment of a specific case within one's discipline (e.g., pastoral care, social work, psychology, nursing). The implications of initial success and effectiveness in the specific, foregoing cases are far-reaching. A larger, more comprehensive assessment might yield very specific information about the efficacy of interventions to enhance positive, religious coping in AD.

Acknowledgment

This article was completed during the first author's sabbatical leave from Malone College. Many thanks are due.

Notes

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35W. M. Clements, "Aging and the Dimensions of Spiritual Development" in *The Role of the Church in Aging*, ed. M. C. Hendrickson (New York: The Haworth Press, 1986). For descriptions of faith development and normal aging, see also, C. Bruning and K.Stokes, "The Hypotheses Paper" and J. W. Fowler, "Stages of Faith and Adults' Life Cycles" in *Faith Development in the Adult Life Cycle*, ed. K. Stokes (New York: W. H. Sadlier, 1983).

³⁶Davis, My Journey into Alzheimer's Disease.

³⁷Ibid., 110–1. Note that prevailing upon a person to examine issues associated with positive coping and religious development is not necessarily the same as sharing faith for the purposes of catalyzing conversion. Indeed, the issue of whether religious conversion is possible when someone is experiencing Alzheimer-type dementia (especially in the middle and late stages) is quite different than the issue set forth here. One might very well believe that religious conversions are still possible for individuals with AD, without also believing that those individuals are cognitively equipped to learn new strategies for religious coping. Davis's writing would suggest a critical role for communicating support through nonverbal comfort. He seemed to eschew the notion that cognitive arguments for repentance could effect change in either the faith-state or coping strategies of a person with AD.

38See Janicki and Daulton, Dementia, Aging, and Intellectual Abilities, 12 and Appendix 2.

³⁹P. V. Rabins, M. D. Fitting, J. Eastham, and J. Zabora, "Emotional Adaptation Over Time in Care-givers for Chronically Ill Elderly People," *Age and Ageing* 19 (1990): 623–7.

⁴⁰Reisberg, et al., "The Brief Cognitive Rating Scale (BCRS)."

⁴¹D. S. Knopman and M. J. Nissen, "Implicit Learning in Patient's with Probable Alzheimer's Disease," *Neurology* 37 (1987): 784–8.
⁴²Ibid.

⁴³M. Goldsmith, "When Words Are No Longer Necessary," *Journal of Religious Gerontology* 12 (2001): 139–50.

⁴⁴The first case described herein was presented as part of an invited talk entitled, "On Faith Issues and Dementia," at Geneva College, Beaver Falls, PA (March 1998).

45M. K. Baker and L. S. Seifert, "Syntagmatic-Paradigmatic Reversal in Alzheimer-type Dementia," Clinical Gerontologist 23 (2001):
65–79; L. S. Seifert and M. K. Baker, "Art and Alzheimer-type Dementia: A Longitudinal Study," Clinical Gerontologist 26 (2002):
3–15; and L. S. Seifert, B. M. Drennan, and M. K. Baker, "Compositional Elements in the Art of Individuals with Alzheimer-type Dementia," Activities, Adaptation, and Aging 25 (2001): 95–106.
46 American Psychological Association, "Ethical Principles of

⁴⁶American Psychological Association, "Ethical Principles of Psychologists and Code of Conduct"; and for a general model of a person's physical, psychological, and spiritual aspects in relation to God, see Koenig, *Aging and God*, 107.



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