

CLINICAL COMMENT/CASE STUDY



Spiritual Diversity and Living with Early-Stage Dementia

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ABSTRACT

Attention to spiritual diversity is necessary for the provision of culturally informed clinical care for people with early-stage dementia and their family members. In this article, an evidence-based theoretical framework for conceptualizing spiritual diversity is described in detail (Pargament, 2011). The framework is then applied to two clinical case studies of people living with early-stage dementia to elucidate the multilayered components of spiritual diversity in this population. The case studies were selected from a larger mixed-methods study on spirituality, positive psychological factors, health, and well-being in people living with early-stage dementia and their family members. To our knowledge this is the first systematic attempt to apply a theoretical framework for understanding spiritual diversity in this population. Implications for clinical practice are provided.

KEYWORDS

Alzheimer's disease; culture; dementia; diversity; spirituality

Introduction

An evidence-based theoretical framework for conceptualizing spiritual diversity is described and applied to two clinical case studies of people living with early-stage dementia who participated in mixed-methods study on spirituality, positive psychology, and living with dementia (See McGee, Myers, Carlson, Funai, & Barclay, 2013 for additional information). This article represents the first systematic attempt to utilize this framework for elucidating the multilayered components of spiritual diversity in this population. We have intentionally simplified the framework to focus on the most salient concepts for application to this population. For a more extensive presentation of the framework, readers should consider Pargament's seminal book *Spiritually Integrated Psychotherapy* (2011). Recently, the framework was employed to demonstrate spiritual diversity among older adults (McGee, Pargament, & Silverbook, 2016). The phrase *people living with early-stage dementia* refers to people in the beginning stages of a progressive neurocognitive disorder, such as Alzheimer's disease (AD), and their family members.

Spirituality is manifest in unique ways by each person and among distinct religious or spiritual

groups (e.g., Buddhism, Christianity, Hinduism, Islam, Judaism, WICCA, among others). It has been considered an important aspect of life in cultures around the world and is associated with several critical cross-cultural dimensions (see Tarakeshwar, Pargament, & Mahoney, 2003). It can be a source for health and well-being as well as a source for problems. At its core, spirituality may be conceptualized as a “*search for the sacred*” (Pargament, 2011, p. 32). Both theistic (e.g., God, gods, higher power, Spirit, etc.) and non-theistic representations (e.g., the Universe, divine source, nature, etc.) may be at the center of a person's *sacred core* from which other aspects of life radiate to form a *sacred ring* (see Figure 1).

Each person's sacred core and ring are unique and influenced by multiple contexts and cultures (e.g., race, ethnicity, place of birth, nationality, communities, religious and spiritual traditions, family values and beliefs, activities and interests, life experiences, etc.). Almost any aspect of life can take on sacred significance through the process of *sanctification* or association with the sacred core (Mahoney et al., 2005; Pargament & Mahoney, 2005). For example, a person may perceive the divine when viewing a snowy mountain peak, hearing the waves of the

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Figure 1. Spirituality, the sacred domain.

Note: Adapted with permission from Pargament (2011).

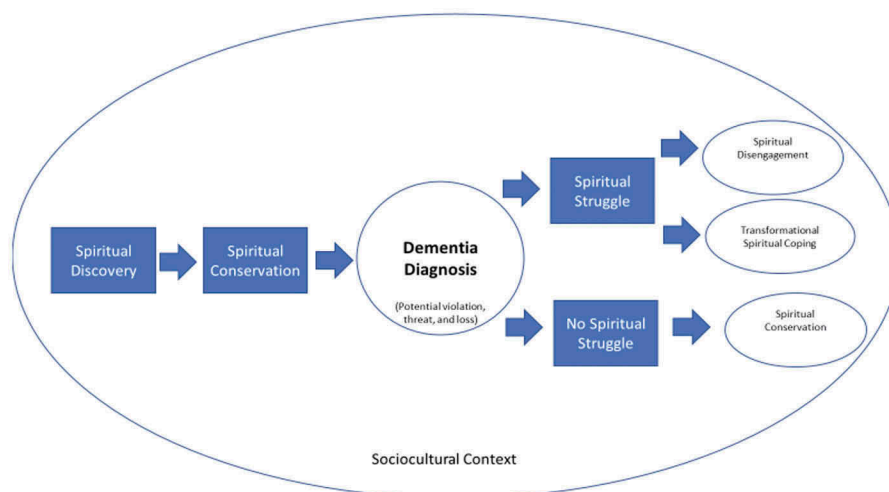


Figure 2. Model for understanding spiritual diversity and early-stage Dementia.

Note: Adapted with permission from Pargament (2011).

ocean, sitting quietly in a worship service, watching a lighted candle, or singing a hymn from childhood. Another may view the baking of bread and consuming it with loved ones as a sacred gift from God. Values, beliefs, character traits, and strivings may be deemed sacred if they are associated with what is perceived as Holy for that person.

Over the lifespan, individuals tend to *search for the sacred* in a distinct, dynamic, and active manner (Lomax, Kripal, & Pargament, 2011; Pargament & Mahoney, 2002). Four

components of this process will be reviewed here: a) discovery; b) conservation; c) spiritual struggle; and d) spiritual coping (See Figure 2). *Discovery* often begins in childhood; however, it may occur at any point in the lifespan. Once discovered, the sacred may become a powerful organizing force in peoples' lives serving as a resource for meaning and support. It may serve as the wellspring from which positive spiritual emotions are drawn (e.g., awe, uplift, gratitude, humility, among others).

People are motivated to *conserve* or hold on to the sacred once it has been discovered. It becomes a habitat, a place to be, a place people long to return. Most spiritual traditions view the idea of the path as essential for conservation (Schmidt et al., 1999). For example, individuals may be inclined to learn about life's greatest truths through reason, intuition, or revelation (the pathway of knowing); enact their religious or spiritual understandings of the world through ritual and practice (the pathway of acting); and connect with family, friends, and others in their spiritual community (the pathway of relating). Each person has a preferred pathway for connecting with the sacred, or what Pargament refers to as a spiritual orienting system (2011). They may simultaneously engage in more than one pathway—and at different points in life a specific path may become more predominant.

The perceived loss or violation of what is considered sacred to a person or a community can result in disorientation, profound emotional pain, and questioning one's value and purpose in life (Exline, 2013; Pargament, 2013). Trauma or transition, including illness and disability, can severely test a person's sense of the sacred and lead to *spiritual struggle* which may temporarily or permanently result in that person disengaging from their spiritual path. Spiritual struggle can be manifest within a person, between the person and other members of their spiritual community, and with the supernatural (Pargament, 2013; Schmidt et al., 1999). Spiritual struggle can take many forms such as negative thoughts or feelings about God; concerns that the Devil or evil spirits are creating the difficult situation; negative feelings about one's spiritual community; anguish from doubting or questioning one's beliefs; and concerns about ultimate meaning or the purpose of one's life (See Exline, Pargament, Grubbs, & Yali, 2013).

During times of loss, violation, or threat, people may utilize various forms of *spiritual coping*. An example of spiritual coping is benevolent spiritual reappraisal which involves redefining a stressor (through spirituality) as potentially beneficial (Pargament, Koenig, & Perez, 2000). For

example, one elder diagnosed with early-stage dementia told us that he had the opportunity to focus more on his spiritual life now that he had retired (even though the reason for retirement was because he had difficulty performing his job secondary to his cognitive changes). Spiritual support, another spiritual coping strategy, involves searching for love, care, and connection with one's spiritual community (See Pargament, 1997 for an extensive discussion of spiritual coping).

Case Studies

Case Study 1

Mrs. A is a 58-year-old, widowed, African-American woman who worked in the field of Social Work before retiring. She began noticing mild difficulties with attention/concentration, language, and memory approximately 2 years before she received evaluation. The decision to seek out medical attention was made after she participated in a meditation workshop and had difficulty comprehending instructions and expressing herself. This situation resulted in significant distress for Mrs. A, because some members of the meditation group teased her when she had word-finding difficulties and forgot the instructions to a specific meditation practice. She received a comprehensive diagnostic workup at a clinic including neurological evaluation, neuropsychological assessment, labs, imaging, and other tests to identify the source of her cognitive changes. She was diagnosed with early-onset, early-stage Alzheimer's disease (AD) and depression, was prescribed medications to assist with cognition and mood, and was referred for counseling to assist with coping, adjustment, and planning for the future. Other pertinent history was that she had served as her husband's primary caregiver after he sustained a severe head injury in a car accident when they were both 35 years of age. Her husband died of complications related to the head injury a year later. She has experienced episodes of depression since that time especially around the anniversary dates of his accident and death. Involvement with her meditation group had been a significant source of spiritual comfort prior to the onset of her cognitive changes.

Case Study 2

Mr. B is a 72-year-old, married, Caucasian man who recently retired from his insurance business after his partner noticed that he was not following through with important paperwork and arguing with his clients on the phone. His wife noticed that he was beginning to repeat himself often and becoming confused about the dates and times for their social activities. The couple decided to seek a comprehensive diagnostic workup to determine the etiology of his cognitive and behavioral changes, and he was eventually diagnosed with early-stage AD. Prior to the diagnosis, he was a lay leader in a church where he volunteered much of his time to planning events for the congregation. After he was diagnosed with AD, he experienced an episode of severe depression and was seen for counseling to assist with coping and adjustment.

Discussion

In this section, selected components of the model (discovery, conservation, spiritual struggle, and spiritual coping) will be applied to demonstrate how attention to spiritual diversity illuminates the process of adapting to living with early-stage dementia.

Discovery

As previously noted, the sacred is discovered at different points over one's life and can be manifest in a multitude of ways. The woman in the first case, Mrs. A, recalled that she first became aware of the sacred in the family garden around the age of five. She stated, "When I walked in the garden, I became aware that I was one with the grass, the trees, the flowers, and all living things. I noticed a shimmering white light as the butterflies beat their wings and somehow knew they were divine messengers from the universe." Soon after her husband died, she cried out to "the universe" and experienced the presence of "an angel" which became manifest to her and offered her comfort and guidance for many years.

The man in the second case, Mr. B, recalled that he first discovered "God" as a teenager at the church he attended with his parents. He recalled the pastor encouraging congregants to "accept Jesus as their personal savior" during an evening service, going to the front of the church to do so, and experiencing a sense of love.

Conservation

Conservation, as previously defined, is the means through which a person strengthens and preserves their connection with the sacred. Mrs. A described herself as an "empath" and reported that she relied heavily on her intuition or "gut" to connect with the Universe (pathway of knowing). This ability was facilitated through the practice of meditation and yoga (pathway of acting), contemplating nature (pathway of knowing), and receiving support from her spiritual community (pathway of relating).

The pathway of acting was Mr. B's preferred way of connecting with God. Specifically, he participated in religious traditions and rituals at his church (e.g., praying together as a congregation, singing hymns). Also, he consistently volunteered to coordinate service activities for homeless people and men in prison as an expression of his faith.

Spiritual Struggle

Mrs. A shared several clear examples of spiritual struggle related to living with early-stage dementia. Most notably, she reported that she was discouraged because her cognitive changes made it more difficult for her to feel the presence of the angel when she meditated by herself. She shared that participating in her meditation group helped to some degree, because she "did not have to generate the connection on her own." However, during a mindfulness meditation workshop, she experienced word finding difficulties, and some members of the group laughed at her which made her feel self-conscious. This situation resulted in emotional distress, and she chose to disengage from the group. Soon afterwards, she had to move to assisted living and no longer had

access to the meditation room in her house or her garden. She reported that she felt “spiritual desolation” when she moved to the assisted living center.

Mr. B shared that he considered his diagnosis of AD a “death sentence” and became angry with God. He asked God, “Why did you bring this on me and my family? Have I not always been faithful to you”? He ceased to participate in any activities related to his church for several months following the diagnosis and became increasingly depressed and despondent.

Spiritual Coping

After disengaging from her meditation group and moving to assisted living, Mrs. A was encouraged by her counselor to attend an adult day program suitable for people with early-stage dementia. She began participating in a small group that read Scripture and other writings from several religious traditions out loud each day which she found comforting. The members of the group all had cognitive changes and were supportive when a member of the group “got off track” or had “word-finding” difficulties. Additionally, she participated in a gardening program that helped her reengage with nature. She eventually reestablished herself with a spiritual community through a Unitarian church. She reported that people at this church were more accepting of her cognitive changes than her meditation group. Also, she discovered that she benefited from participating in other spiritual practices such as burning sage to “clear herself of negative energy” and walking a labyrinth to remind herself that she was still on her life path.

Mr. B indicated that he was eventually able to pray to God to help him cope with the anger he felt after being diagnosed with AD. He said, “It was like there was a steel trash can over my head, over my body, and He lifted it off and put it down [on the ground].” This powerful experience of emotional healing inspired him to speak out, as a person with AD, against stigma and to serve as a positive advocate for others for the remainder of his life. He shared his story with many churches in his local community with the assistance and support of his wife.

Clinical Implications

Clinicians should consider multiple points when addressing spiritual diversity among people living with early-stage dementia. First, it is important to ask what they consider to be most sacred in their lives. In doing so, a host of resources and strengths may be uncovered and tapped into potentially leading to better health and wellbeing. Likewise, spiritual struggles may be identified and potentially addressed.

Second, learn about people living with early-stage dementia’s spiritual pathways. Be alert to both traditional and nontraditional spiritual pathways. If a person with dementia is having difficulty following a preferred spiritual pathway due to disease or disability, you could suggest that they engage in another spiritual pathway. You can potentially help them develop spiritual compensatory strategies which may positively impact health and wellbeing when they are no longer able to engage in a previously employed pathway. For example, we have observed that some people with AD may more easily connect with sacred rituals such as kneeling for prayer, lighting a candle, singing a sacred song from childhood (the pathway of acting) rather than engaging in the study of scripture or other religious or writings (the pathway of knowing).

Third, consider how past and more recent losses and stressors are impacting the lives of people living with early-stage dementia from a spiritual perspective. Ask yourself, has this person experienced a spiritual struggle in the wake of a dementia diagnosis? Affirm their willingness to engage in a discussion about the nature of the loss, their feelings about the loss, and how the loss relates to their spirituality. Normalize any feelings of anger with God or higher powers, as these feelings may be a source of great distress.

Fourth, encourage people living with early-stage dementia and their families to draw on their spiritual resources to sustain/conservate their faith and spirituality. Remember that maintaining a positive relationship with the transcendent and being a part of a spiritual community may serve to facilitate coping. Sacred relationships, such as these, tend to

fall into several categories for this population: a) relationships with the transcendent (i.e., God, higher power, spirit, nature, etc.); b) relationships with the spiritual community (i.e., church, synagogue, mosque, spirituality group); c) relationships with significant others (i.e., family, friends, and others); and d) relationships with the self (McGee & Myers, 2014; McGee et al., 2013).

Fifth, it is possible that people living with early-stage dementia may consider their relationship with you the clinical provider to be sacred. Several authors have identified and described the elements of this spiritual connection such as: a) the capacity of the provider to be mindfully attuned to and present for the patient (Bruce, Manber, Shapiro, & Constantino, 2010); b) the ability of the provider to offer therapeutic inspiration (O'Grady & Richards, 2010); c) the ability of the provider to relate wholeheartedly to the patient in the fullness of their humanity with an I-Thou orientation (Buber, 1970); and d) a focus on transformational moments (Stern, 2004).

Finally, remember that spirituality or the search for the sacred is not static or linear but is instead a dynamic multilayered process involving discovery, conservation, spiritual struggle, spiritual coping, and rediscovery. We encourage clinicians to consider including spiritual assessment as part of the evaluation process for people living with dementia. Likewise, clinicians can consider making meaningful recommendations which address spiritual diversity within the context of cognitive decline in their treatment plans.

In closing, we advocate for an integrated approach to working with people who are living with dementia and their family members—an approach infused with kindness, compassion, and the acknowledgment of the unique diversity of each person within the fullness of their humanity. An openness to and awareness of the rich spiritual diversity and heritage that each person brings to the table is a key to validating personhood throughout disease progression.

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