

¹ Baylor College of Medicine, Department of Neurology, Alzheimer's Disease and Memory Disorders Center, Houston, TX

² Amazing Place Daytime Memory Care Center, Houston, Texas

³ Baylor University, School of Social Work, Waco, TX

⁴ University of Texas, Houston, TX

BACKGROUND

- Previous research has demonstrated an association between spirituality and cognitive and emotional functioning in people with Alzheimer's disease (AD) and other dementias (Kaufman et al., 2007; Coin et al. 2010).
- However, to our knowledge there is no published data to date that provide an explanatory model.
- In this study, spirituality was defined broadly as "a search for the sacred" (Pargament, 1999).
- The sacred can be experienced in ordinary day-to-day encounters with people, places, and objects that are imbued with meaning as well as transcendent reality, higher powers, or guiding life philosophies.

METHODS

Participants:

- 28 people with mild AD participated in the study.
- They were recruited from the Alzheimer's Disease and Memory Disorders Center at Baylor College of Medicine, Amazing Place Memory Care Center, Buckner Retirement Community, the Alzheimer's Association of North Texas, Interfaith Carepartners, and Sid Gerber and Associates.

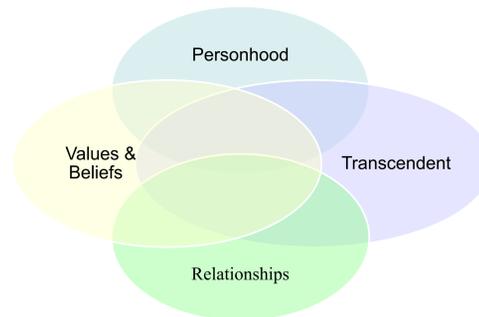
Data Collection:

- After giving written consent, participants received a structured interview called the Dimensions of Living with Dementia (DLD). See AAIC poster on the development of this interview.
- Interviews were conducted in a private office space and took on average 45 minutes to complete.
- All interviews were transcribed by a trained transcriptionist and later audit checked by a second trained transcriptionist.

Analysis:

- 3 researchers independently read and coded all interviews.
- The team selected ATLAS.ti, version 6 (Muhr, 2008) as the platform for qualitative data analysis.
- Initial codes and definitions served as the basis for applying the constant comparative methods (Glaser & Strauss, 1967; Strauss & Corbin).
- 12 telephone conversations were conducted to process insights from individual analysis and triangulate the analysis to formulate 20 axial or parent codes.
- This iterative process of text-to-code and code-to code revision by researchers increased the trustworthiness of our findings.
- Additionally, the data from interviews, observations, and field notes were triangulated in order to provide contextual accuracy.

THEMES ON SPIRITUALITY AS A RESOURCE



SACRED VALUES & BELIEFS

"What does spirituality mean to me? I see it as a driving force. He [God] is the perfection in your life, the peaceful coexistence of striving for orderliness and being and example to my children."

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

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

AFFIRMATION OF PERSONHOOD

"It is a great family. It is a total family...everyone is considered important."

"Everybody is very nice to me. You know, and I enjoy hearing the preacher preach...and I love the little ones who make it up there and do their little thing. You know, on the stage. I love that."

CONNECTION WITH THE TRANSCENDENT

"As long as I start my day off with His protection and understanding, He won't lead me the wrong way... I feel like He is going to protect me as much as He can."

"When the sands are shifting in other parts of your life [referring to the progression of AD], you know why God is the rock."

"I look back at all of that [adjusting to the diagnosis of AD], and I think my relationship with God is hopefully very good now, and especially after I made that prayer. It just totally relaxed me. I am serious. It was like there was a steel trash can over my head, over my body, and He lifted it off and put it down. It was a big step [towards acceptance and peace with the diagnosis]."

SACRED RELATIONSHIPS

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

"The relationship with friends is sacred. Friendships and loyalty and being loyal to friends...I guess those are the things I consider most sacred."

"What is most sacred to me is to make my wife happy."

FINDINGS

- Most participants in this study self-identified as being both religious and spiritual when queried. However, some were unable to distinguish between these two constructs.
- People with mild AD can actively engage in discussion about how spirituality influences their experience of living with AD through open-ended questions (as in the DLD Interview).
- They remain deeply devoted to a relationship with the transcendent (i.e., God, higher power, spirit).
- Their faith communities continue to be important to them.
- They value and benefit from the sacred aspects of their day-to-day lives;
- Their core spiritual values, beliefs and practices can serve as a resource for helping them adapt to the uncertainty of living with AD.

IMPLICATIONS

- Spirituality and faith are important aspects of diversity in people with AD.
- Spirituality and faith can serve as a resource for adjusting to a diagnosis of AD through models for understanding human suffering, comfort and support, hope for a cure and a good death, and courage to continue living life to the fullest.
- There is a need for spiritually integrated assessment in clinical and pastoral settings that serve people with mild AD.
- Integrating spirituality into clinical interventions for people with mild AD may be effective in decreasing some of the emotional and behavioral symptoms of AD, especially when people with AD are experiencing spiritual struggles.
- Once spiritual resources are identified, clinicians can work to reduce barriers to accessing these resources for people with mild AD (i.e., transportation to continue to participate in spiritual or faith-based practices).
- Sensitivity must be taken when discussing issues of spirituality and faith with people who have AD with clinicians emphasizing the world-view of the patient rather than their own world view.
- There is a rich opportunity for research on the spiritual dimensions of living with AD including the role of spirituality across the course of AD (from diagnosis to death), in different types of dementia, and across diverse social, ethnic, and religious cultures.

**For More Information contact jmcgee@bcm.edu or dennis_myers@baylor.edu