Spirituality as a Coping Mechanism for Alaska Native Caregivers

Benjamin Fife MS2 • Jordan P. Lewis, PhD

WWAMI
Introduction

• Caregiving has been associated with negative physical and mental health outcomes due to chronic stress (Schulz & Sherwood, 2008)

• Ethnic groups report more barriers in accessing help for dementia caregiving (Mukadam et al, 2011)

• Few studies have developed caregiver interventions for ethnic groups (Nápoles, 2010)

• Spirituality has proven effective in reducing stress (Tuck et al, 2006)

• Health care professionals feel they should address spiritual needs in dementia care but report lack of confidence (Bursell & Mayers, 2010)
Dementia Among Alaska Native People

• Spirituality is a component of aging well for Alaska Native elders (Lewis, 2011)

• Rising prevalence of dementia in Alaska Native people, but no current data collected.

• 61% of caregivers in Alaska are caring for someone with ADRD (AK DHSS, 2015).

• In Alaska, an estimated 128,000 informal caregivers provide unpaid care valued at $1.1 billion (AARP 2015).
Purpose of Study

The aims of this study are to:

(1) Explore stressors experienced by Alaska Native people caring for someone with ADRD

(2) Explore role of spirituality in coping with those stressors
# Methods

<table>
<thead>
<tr>
<th>Study Design</th>
<th>Exploratory, qualitative research study</th>
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<tr>
<td>Participants</td>
<td>Recruited 11 caregivers through the Alzheimer’s Resource Center of Alaska, Fairbanks Native Association, and the Bristol Bay Area Health Corporation.</td>
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<td>Criteria</td>
<td>1) Self-identified as an Alaska Native person, 2) provided direct care for a family member with ADRD, and 3) were 18 years or older.</td>
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<td>Data Collection</td>
<td>Semi-structured interviews in person and telephonically; lasted approximately 60 minutes in three communities: Anchorage, Fairbanks, and Dillingham.</td>
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<td>Analysis</td>
<td>Interviews were recorded and transcribed verbatim for thematic analysis.</td>
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Results

Two major themes:

(1) Alaska Native caregivers reported chronic stressors related to caregiving

(2) Caregivers used a variety of spiritual practices to cope with stressors
Chronic Stressors

Poor Health:
• Sleep deprivation
• Not eating enough
• Do not go to the doctor
• Friends and neighbors tell them to take care of themselves

“"The not sleeping thing? I am the grumpiest person in the world if I'm not sleeping well, and if I'm not sleeping well, I'm not eating, I'm not—I'm just blah. I'm just not doing well mentally. That was probably my biggest struggle was the mental health aspect, which was foreign to me, because I've never had to deal with that before.”
Chronic Stressors

Lack of Support

• Feel they provide care by themselves - isolation
• Constant worry
• Unable to leave family member alone
• Extended family does not offer help
• Dealing with changing personality
• Difficulty managing other commitments (school, work, children, etc.)
• Extra expenses related to care and household upkeep

“Right now I figured out I am grieving for him already, you know. That grief. 'Cause I know he will eventually die from it. And you know he might die seven years from now. But I think I am grieving already. And I think I'm grieving for the fact that he's not himself and I miss that part. I miss talking to him. I miss going fishing with him.”
Chronic Stressors

Lack of Education

• Figure out tricks and techniques to keep family member safe
• Difficulty navigating government support systems
• Not prepared for impact on self and family
• Family members do not understand ADRD

“"It would be great if there was some sort of guidebook on what to do next. Like a checklist that you can go down of vital things that you need to have done for them before they completely lose their memory because we were pretty much left to our own devices of having to figure out the next step.”
Coping through Spiritual Practices

Types of Spiritual Practices

- Prayer
- Reading
- Attending worship services
- Songs (religious and traditional)
- TV programs
- Yoga
- Counsel with religious leaders and friends
- Visitors from congregation
- Taking a walk outside, appreciating nature
Coping through Spiritual Practices

Reported impacts
• Improved mental health, even physical health
• Provided understanding of death and dying
• Spiritual practices helped loved one too

Difficulties
• Later stages of ADRD made attending church too difficult
• Younger caregivers distanced from organized religion
  • Still helped family member participate in religious practices

“They were singing our Native songs in his room one day, and he couldn’t hear. He was almost deaf, and as he was passing, they were singing, and they weren’t singing really loud, and he could hear them. I could see him moving, and I could hear him trying to sing.”
Conclusions

• Chronic stress is common among Alaska Native caregivers
• Use of spiritual practices are a primary coping resource for caregivers
• This study helped us understand the experiences, benefits, challenges, and lessons of Alaska Native caregivers
• Learn what is required to support someone with ADRD
• Understand the role of spirituality in their lives.

“I mean, I never felt that mom was a burden. Because we—I mean, we told her, we have five kids, and tons of extended family. We always said that, you know, she lost her parents when she was 2 and 3 to influenza. I never got to know my grandparents, and my kids loved her. And we said we're gonna do everything we can to support her and, you know, thank God every day that we had her.”
Recommendations

- Encourage family caregivers to seek out spiritual practices that work for them to cope with chronic stressors
- Encourage health care providers to ask patients and family members about religious preferences
- Encourage religious and spiritual organizations to offer programs and support groups for caregivers
  - Also offer spiritual and religious activities for those with ADRD
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Sources


