

Alaska Native Dementia Caregivers: Their Strengths, Blessings, and Directions for Future Training and Education

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Presentation Outline

- About me
- Who are our caregivers
- Impacts on caregiving experience
- Sources of caregiver wellbeing
- Wisdom of our Caregivers
- Training & Education
- Closing thoughts

About me



- Unangax/Aleut
- Commercial fishing background
- Raised among Elders in my family and community




Caregiving

- **90%** of elder care in Indian Country is provided by family members
- **29%** of general U.S. population provides elder care to family members

Why keep family members at home?

- Respect wishes of Elder
- Maintains family unity, community connections
- Elder surrounded by loved ones
- Elders' presence maintain community wellbeing

Literature

- Caregiving implies one direction of benefit:
 - Caregiver  Care recipient
- In reality, caregivers also experience rewards
- Lessons learned and rewards from caregiving are not expected when stepping into role as caregiver
- Lessons and rewards are not time-sensitive; they arise anytime

Traditional beliefs about caregiving

- Elders are contributing members of the family and community; honor and respect our Elders.
- Living at home, surrounded by loved ones, is the Elders' wish and contribute to family & community wellbeing.
- Family respect and honor their Elders and support them to age with dignity and respect their wishes.

Impacts of historical events on Caregiving

- Decline in transmission of language, history, oral culture
- Change in family structures
- Loss of family history, traditions, stories, recipes
- Historical trauma, abuse, neglect
- Dietary changes
- Mistrust in health care system

Caregiver Strengths

- Family
- Community
- Connection to Elders
- Subsistence
- Spirituality and Religion

Strength 1: Family

- Supporting each other, share responsibilities
- Spending time with other family members
- Asking family members to provide support, respite

Strength 2: Community

- Receiving support from community
- Maintaining honor and respect by family & community
- Engaging family in events
- Watching out for those with dementia
- Intergenerational programming

Strength 3: Connection to Elders

- Spending time with the Elder is healing
- Learning family recipes
- Hearing family stories, learning history
- Going for a ride/walk
- Grandchildren spending quality time with grandparent

Strength 4: Subsistence

- Putting food away based on Elder's teachings
- Receiving foods, sharing resources
- Giving to others (stories, knowledge)
- Spending time on the land – healing, grounding

Strength 5: Spirituality & Religion

- Increasing mental strength
- Providing a sense of community
- Coping strategy
- Offering respite
- Receiving support
- Connecting to a higher power
- Connecting to family
- Serving as a coping strategy

Caregivers' Blessings

- Provide the life Elder wants
- Family healing
- Intergenerational connections
- Learn history, family stories

Wisdom of our Caregivers

“I had a lot of very valuable time with my grandmother, and out of all of my cousins, I'm the only one, aside from my brother, that can say that. We took the time to spend time with her, even with everything going on in our lives. We were there to listen to her stories, even if we've heard it 20 times that day, and those are memories I will have for the rest of my life.”

Wisdom of our Caregivers

“I'm so glad I spent time with my grandmother. She might have driven me crazy at points in my life, but I wouldn't change it for the world.”

Wisdom of our Caregivers

"I am glad that I have given my parents good caregiving so they can see this day, to actually witness this day, and know all this work was worth it. I was able to help my parents live to see moments and create new moments."

Wisdom of our Caregivers

“Being around my mom was such a joy. We had our own spats throughout our lives together, but this was my chance to be with my mom, so I didn't care how many times she told me the same story. None of that made any difference to me because I was just happy to be with her and to help her was a special to me that and there was no drawbacks to it. It was just something really fun to do, just to get closer to her.”

Weaving generations together

“Caring for your Elders is important because it affects not only my generation and then my grandkids' generation and then their kids' generation –it's the indigenous way of thinking; seven generations forward and seven generations back, all these people are affected by my Mom being around for three or four more years. I'm not trying to make a big deal out of it, but it's one way of thinking when you go into the profession of taking care of another life or trying to help that person live a quality of life that is meaningful.”

Weaving generations together

“She said that was probably the best time in her life that she got to spend with her grandma. She said, ‘Thank God we had grandma.’” Because that was her crutch when her dad left, and she had that support and something to hold onto.”

Wisdom of our Caregivers

“I never felt that mom was a burden. because we have five kids, and tons of extended family. She lost her parents when she was 2 or 3 to influenza. I never got to know my grandparents, and my kids loved her. And we told her that we are going to do everything we can to support her. We thank God every day that we had her in our lives.”

Wisdom of our Caregivers

“Whatever wisdom and knowledge they can share with us, that they remember. And sometimes they tell us over and over and over, and maybe they know it’s for our good and sometimes it’s dementia. And we can’t say, ‘Oh, we just heard that, Grandpa.’ You know, having respect for them, we let them repeat themselves over and over and over so we get it in our head.”

Lessons learned from your second chance

- Caregiving provides opportunities to begin to heal historical trauma
- Improve, strengthen relationships among family members
- Families learn history and explore ways to heal, improve communication
- Multiple generations positively impacted by Elder and the cognitive changes related to dementia

Lessons learned from your second chance

- Repetition in storytelling ensures family history is preserved
- Despite dementia-related changes, they are still our family and have a common history
- Even in challenging times, there are glimpses and reminders of good memories

Directions for Training and Education

- Improve access to culturally responsive, affordable, quality respite care
- Appropriate, accessible, and on-going education and training to help caregivers meet their responsibilities
- Engage caregivers in education and training development, policy making, trainings, share their stories
- Engage caregivers to develop and test interventions to reduce burden, improve competence, and adaptation
- Encourage caregivers to highlight successes and benefits

Closing thoughts

- Caregiving is an opportunity to give back to those who took care of you.
- Caregiving is a natural part of the Indigenous way of thinking.
- Caregiving is a time of constant growth and education, self reflection, and healing.

Closing Thoughts

- Benefits arise during and after the caregiving experience and remain influential.
- Lessons taught to us by our Elders throughout life play a role in caring for others.
- Spending time with family provides opportunity to heal from past and pass on a new understanding of history

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Thank you for your time!
Any questions?

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