

Educational Program to Promote Resilience for Caregivers, Family Members, and Community Members in the Care of Elderly Native Americans who are Experiencing Memory Loss and Cognitive Decline

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ABSTRACT

Partnering with Adopt-A-Native-Elder Program (ANE) afforded the opportunity for tribal and academic partners to explore the role of resilience in contributing positive health outcomes in the Navajo communities who are experience memory loss, cognitive decline, and/or dementia as they age. The purpose of this project was to provide an educational program to build and nurture resilience for caregivers and their Navajo Elder's in a manner to maintain their traditional spirit and cultural lifestyle. Using a community-based participatory framework grounded through the lens of compassion energy with ANE and focusing on Navajo Elder's and their caregivers for this project allowed for a better sense of how caregiving for Native Elders with memory loss and cognitive decline is manifested and experienced.

Keywords: Resilience, Memory loss, Cognitive decline, Navajo Elders, Caregivers, Cultural humility, Compassion Energy

Introduction and Purpose

Forgetting things such as a name or a phone number or misplacing an item can be a minor inconvenience, yet age-associated changes in cognitive abilities can evolve into a major source of personal worry. Forgetfulness at older ages is often related to a decline in cognition, which can have a significant impact on mental functions such as decision making, memory, attention, orientation, problem solving, thinking, understanding, learning, and remembering. Cognition is multidimensional and involves interrelated abilities that play different roles in processing information and in behavior. Cognitive decline affects not only the individual but also the caregiver, family, and community.

The American Indian (AI) and Alaska Native population now totals 5.2 million people (U.S. Census, 2012). As the AI population grows and ages, the impact of cognitive decline is

increasing (IOM, 2015). Caregivers, family members, and community members are the informal caregivers of those with cognitive decline, and they experience stress and burden, as well as benefit and blessings.

American Indians (AIs) have cared for their elders for hundreds of years. The word caregiver is a new name given to an age old AI practice. Ironically the name is fraught with meaning either unknown or threatening to many family or informal caregivers (Ryser, Korn, & Berridge, 2014). Unfortunately, tribal, state, and federal laws, policies, and practices sometimes prevent AI caregivers from gaining access to personal services and support needed that would enable good health and quality of life (Ryser, Korn, & Berridge, 2014). When non-native county agencies offer such assistance for AI caregivers, these services have often been rejected on grounds of inappropriateness or intrusiveness. Generalized resistance appears to arise from the belief that caring for a family member is a deeply private and personal matter, of primary concern to the immediate family. The role of a person taking care of a family member is often determined by cultural norms. For example, in some communities it would be unthinkable to receive a wage or salary while taking care of a family member. Despite such cultural norms, it is quite clear that tribal family caregivers suffer considerable stress from financial and other burdens. Tribal budgets and state/county agency budgets do not include support and services for caregivers. The consequence can lead to declines in caregiver health and declines in the quality of life and necessary support for the elder receiving care.

The purpose of this paper is to describe an educational project partnership between an academic partner and Adopt-a-Native-Elder Program (ANE). ANE is a private, federally approved, charitable non-profit organization whose purpose is to assist traditional elders in maintaining their traditional spiritual and cultural lifestyles, and thus creates a bridge of hope

between AI and other cultures. ANE has been providing services of which they named Food Runs and Give-Away-Circles for over thirty years and their program allows for all cultures to reach out to one another, share gifts, and mend the broken circle of the relationship with the land and the AI who hold it in sacred trust. As they age, it becomes more difficult for Navajo elders to support themselves on the land. The food runs and give-away-circles are one of ANEs events that support Navajo elders semi-annually. The ANE program supports traditional elders who follow the spiritual and cultural traditions of the Navajo people by providing food, clothing, fabric, yarn, and fire wood to help Elders live on the land in their traditional lifestyle. Through this collaboration, a project was designed to promote resilience among Navajo caregivers of elders with cognitive decline, impairment and/or dementia living on the Navajo Reservation.

Literature Review

Native Americans have a long history of resilience and tradition of respect and caring for their elders. Strong (1984) characterized a coping strategy named passive forbearance that emphasizes acceptance of and adaptation to caregiving activities rather than attempting to control the caregiving situation. Competing responsibilities between caregiving and work or other family duties have been explored as perceived caregiver burden as multidimensional in terms of role conflict and negative feelings toward care recipient. Situations that occur that elicit feelings of embarrassment, getting angry, being uncomfortable with having visitors and can be thought of as an emotional burden (John, Hennesey, Dyeson, & Garrett, 2001).

Literature has addressed the negative consequences of caregiving for the caregiver, but little research has explored the positive experience. Moss (2005) conceptualized Tolerated Illness as a phenomenon that helps explain why some elders will report good-to-excellent health in chronic illness such as dementia. Jervis, Boland & Fickenscher (2010) conducted a mixed method study

exploring the negative and positive aspect of providing care among 19 northern plains AI family members and found that caregivers described low levels of burden and high levels of reward that attributed to their cultural beliefs and attitudes toward elders and caregiving. Hozho is a concept that is described as beauty, balance, peace, wellness, and harmony (Kohn-John, 2010). Life is considered to be full of bad and evil, the beauty (Hozho) helps to fend off the bad and helps one to think positive (Kahn-John, 2010). The complexity of Navajo wellness concept and philosophy is a state of being, a process that Navajo people strive to attain and overcome the challenges of spiritual, mental, physical, emotional, community, and environmental health. An understanding of these ancient wellness philosophies guided the education program by focusing on the positive aspects of health, well-being, and health promotion. Jervis, Boland and Fickenscher (2010) findings of positive caregiving experiences in a community faced with poverty, alcohol disorders, trauma, and cultural traumatization reveals resilience of Navajo elders and the important roles it represents within the community.

Many factors contributes to resilience and successful aging defined as achieving and maintaining a sense of well-being despite age-related challenges (Resnick, 2011; Young, Frick, & Phelan, 2009). Factors of resilience in older people were identified as caring for self, spirituality, orientation to the future, life experience, meaningfulness, caring for others, acceptance, social support, ability to access care and available resources (Van Kessel, 2013). Determining the role that resilience may have in cultural, spiritual, mental, physical and emotional health in AI older adults holds potential to guide health promotion, resilience building, quality of life, and disease prevention efforts in Navajo population. The family resilience model of adaptation includes making meaning out of adversity, having a positive outlook, spirituality, flexibility, connectedness to each family members and community (Walsh, 1998). The aim of

this collaborative project was to support and foster resilience by improving well-being, dementia knowledge, and of caregiver and elders nurturing respect.

The Center for American Indian Resilience (CAIR), an Exploratory Center of Excellence supported by the National Institutes of Health's National Institute of Minority Health and Health Disparities (NIH-NIMHD) is co-administered by Northern Arizona University, The University of Arizona, and Dine College. CAIR afforded the opportunity for tribal and academic partners to explore the role of resilience in contributing positive health outcomes to AIs. CAIR defines resilience as the ability to move forward with renewed energy, a positive outlook, attainable goals to achieve one's dreams, and overcome negative life experiences and political and historical events, with the goal of reducing health disparities among American Indians. Using this definition the project explored ways to promote community capacity to address health promotion among caregivers of Navajo elders with cognitive decline, impairment, and dementia. We used a collaborative educational project to foster resilience and promote the caregivers ability to cope with the challenges of memory loss and cognitive decline in Navajo elders.

Method

The Theory of Compassion Energy was used as the theoretical framework within a community-based participatory approach with the Navajo elders and in the ANE program. The theory of compassion energy (TCE) evolved through a caring concept clarification process and theoretical evolution via a creative synthesis utilizing Rogers' Science of Unitary Human Beings and Caring Science. The three tested attributes that developed from this process of compassion energy are compassionate presence, patterned nurturance, and intentionally knowing the other and self. TCE is described as caregivers who desire to care compassionately by intentionally knowing another's patterned nurturance with authentic presence. The premise of the theory is that human beings are

unitary or irreducible, in mutual process with an environment that is coextensive with the universe, participating knowingly in patterning, and ever evolving through expanding consciousness when caregivers engage with the care recipient from a place of compassionate caring presence, then the caring encounter becomes transformed. The human-environment energy field in this caring encounter creates a positive outcome for the caregiver and care recipient (Dunn, 2009). In the caregiving experience the goal is intentionally provide the caring encounter with compassion, strength, courage, knowledge, and skill to overcome the tendency to care at a distance. By focusing on compassionate care rather than on the tasks to get done or to do, one can stave off the risk of experiencing compassion fatigue. Caregivers will grow and thrive if they understand how to self-generate vigor as compassion energy, preventing compassion fatigue. By melding the conceptually congruent tenets of the science of unitary human beings and caring science a meaningful theoretical conduit through which to view compassion fatigue as mutual process with a capacity of transforming into compassion energy. The act of understanding and nurturing self-generate vigor as compassion energy. Caregivers can find meaning in caring for self and other with the intent to alleviate suffering and celebrate joy. By meaning making, connectedness, and a positive outlook the attributes of compassion energy, compassionate presence, patterned nurturance, and intentional knowing can be compared to Walsh (1998) family resilience model of adaptation includes making meaning out of adversity, having a positive outlook, spirituality, flexibility, connectedness to each family members and community on the Navajo Reservation. A community-based participatory approach allowed the community (ANE) and academic (CAIR) partners to discover the mutual interest in providing education for the Navajo elders and their families regarding cognitive aging. The community-based participatory approach for this project was designed collaboratively to create unique culturally sensitive and respectful responses to Native elders, caregivers, family members, interpreters, and community participants.

The project was a collaborative with the ANE and Navajo communities of Northern Arizona and Utah. Every year for the past 35 years ANE has conducted food runs to the Navajo Reservation to bring elders and their caregiver's an opportunity to gather together on their homeland and share their appreciation in their traditional way for the people who support them. We saw this as an opportunity during the food run that includes a give-away-circle to provide an educational program for caregivers of elders with cognitive challenges. Planning for this program included cognitive education of Navajo interpreters available to engage with those who do not speak or understand English.

The collaborative educational project was open to the elders, caregivers, and community members during each Food Run. Before the Food Run, an orientation and in-service regarding cognitive decline and memory loss and the potential for burden for caregivers was provided for the interpreters. Navajo interpreter were trained in the purpose of the educational information and communication techniques to increase their knowledge and ability to properly interpret the educational objectives. The interpreter also informed the academic partner of beliefs about memory loss, cognitive decline, and dementia from the Navajo perspective. The academic partner taught the interpreters techniques such as asking yes or no questions, being aware of elders' reality and resisting the desire to correct or test memory, which could increase frustration and agitation on the part of the elder.

The educational program goal was to provide an informal educational program about cognitive decline, memory loss, and dementia to foster communication between the elder and their caregiver that would decrease stressors, increase socialization and communication, build resilience, and improve quality of life for both. The program was delivered in two stages, fall 2015 with the elders, and again fall 2016 with the caregivers of the elders. After training the

interpreters the program began by asking the elders if they had any concerns with their memory, or being forgetful. This was accomplished by utilizing set of open ended questions we asked informally to generate an open non-confrontational informative discussion with elders about forgetfulness. The second program conducted fall 2016 targeted the caregivers. The Navajo caregivers spoke English therefore an interpreter was not required, but were available when needed.

Field notes and observations were collected by the academic partner to have an understanding of the Navajo community during the daily food runs and give –away-circles. At the completion of each of the food runs, debriefing with the ANE community partner, interpreter, and the academic partner provided clarity and cultural perspective in providing memory, cognitive decline, and communication technique information. Field notes were the mechanism for collecting thoughts before, during the educational lesson, the activities of the food run, and debriefing after each food run and give-away-circle.

Setting

The Navajo Nation is the largest reservation in the United States .and covers 27,425 square miles of northeastern Arizona, southeastern Utah, northwestern New Mexico, and borders Colorado in the United States (Navajo Division of Health Navajo Epidemiology Center, 2013).. The Navajo Nation can be compared to the size of the state of West Virginia. The scheduled gatherings in Navajo communities of rural Northern Arizona and Southeastern Utah occurred over two years during the fall ANE Food Runs. The Navajo traditional way of life consists of vast stretches of open land among canyons, buttes, spires, mesas as well dry desert like land that comprises the beautiful landscape.

The food run events were held in chapter houses, churches, Dine College, but most were held outside exposed to weather, and crowded into Hogan's. Dilkon, Leupp, Birdsprings, Oljato, Navajo Mountain, Many Farms, Pinon, Tsaille, Sanders, Teesto, and Big Mountain were the communities we traveled to for the food runs and give-away-circles in Fall 2015 and 2016. Most gathering places had no running water or electricity and were accessed down long stretches of dirt roads.

Driving into the deep sacred Navajo land of which is sealed by four mountains one can hear the silence and feel a harmonious pulse. The towering formation of Monument Valley is in great contrast to the majestic red stone walls and lush green floor of Canyon de Chelly of which Navajo elders live and flourish among the beauty of the land. The tradition and respect for Mother Earth gives a feeling of balance and harmony. The academic partner and ANE volunteers would travel in a caravan of 12-20 pick-up trucks and cars carrying supplies to conduct each food run, give-away-circle, and various activities for trading and celebration. As volunteers set up at each location, the academic partner conducted the informal educational program

Elders are able to be part of ANE once they are 75 years of age. ANE supports over 500 elders. During the food runs the elders who participated ranged from 75 to 98 years with average age of 88. In fall 2015 we visited five communities, in fall 2016 we visited eight communities, overall. The fall 2015 targeted the elders about what it means to have a memory problem or be forgetful. The following fall 2016 the caregivers were targeted about their experience of being a caregiver. Caregivers were daughters, sons, granddaughters, grandsons, nieces, nephews, aunts, cousins, and friends. The majority were family members and the entire family (clan) had a shared-role in the caregiving experience described as kinship and valuing the simple life by having basic needs met.

Outcomes

Fall of 2015 was the first opportunity to conduct the program. At each food run and give-away-circle we began with an initial opening question asked of the elders, did they had any concerns about their memory. Our primary finding was that the word forgetful elicited more dialogue than the word memory. The elders consistently reported that they expected to be forgetful with aging, and accepted it. They reported that their family was there to help, therefore they said that they were able to accept and adapt to being forgetful. The family caregivers also reported that they expected forgetfulness, but at times they experienced increasing frustration as communication was challenging. The most common frustrating problem for them was when an elder's forgetfulness (cognitive decline progression) manifested in the form of repetitiveness.

Our second opportunity occurred fall of 2016 when we provided education for caregivers. Family caregivers and elders were interested in learning how to decrease frustration from the loved ones repetitiveness. Education and discussion was individualized for each caregiver as needed. Topics such as staying calm, responding with brief explanations, reminiscing of fond memories, redirection, staying engaged, planning for the future, and safety issues were discussed (Alzheimer's Association, 2015).

The family members had a working knowledge of dementia. Elders were able to join in the discussion when the term forgetfulness was used for memory loss. Both the elder and caregivers asked clarifying questions on how best to approach and manage frustrations, and decrease the caregiver's frustration. Redirection activities, acknowledgement of the level of forgetfulness, observations for patterns to identify actions that were helpful and not helpful in the care of the elder to minimize the frustration also proved beneficial. In this community, caregiving manifested as part of a complex exchange of assistance, and honoring of the elder and

appreciating their wisdom rather than a unidirectional provision of assistance from the caregiver to the elder as is most common in the western-white communities.

Overall, caregivers described low levels of burden and high level of reward in being able to care for their mother, father, sister, brother, aunt, uncle, or grandparent. One daughter stated “I just let her talk, she has good knowledge of the traditional ways”. Another son stated “she doesn’t weave anymore but our tradition keeps going with her stories”. Traditional and Navajo ancient wellness philosophy proved to be very important in the elder (care recipients) and family caregiver relationship.

Evaluation

This project was designed to build resilience for wellness, health promotion, enhance communication, and decrease frustrations to improve positive coping strategies (resilience) and quality of life. There were obvious strengths and challenges in communicating with an elder who only speak Navajo and is cognitively challenged. Caregivers learned strategies for coping with repetitiveness and confusion, such as, distraction, reminiscence, and refraining from testing memory to decrease frustration through open honest respectful discussion. Family members were not aware of any community resources. We provided information regarding how to access the Navajo Nation Council on Aging/Navajo Area Agency on Aging (NNCOA/NAAA).

The challenges of Navajo elder’s was that they expressed concerns of their culture and language being lost. The caregivers and care recipients agreed that sharing the elder wisdom and storytelling were strategies to build cultural resilience and that reminiscing was a way to keep their traditions and culture alive. Participants stated that receiving education on how to communicate to lessen stress and frustration on part of both caregiver and care recipient could not only improve quality of life but also enhance resilience.

Conclusion

The CAIR/ANE/Community partnership offered a unique opportunity to provide an educational program on cognitive decline to communities across the Navajo reservation. The interpreters not only assisted in translating essential information, but also served as cultural experts and liaisons between the academic partner and Navajo participants. The preferred term, forgetfulness, was used in dialogue rather than memory loss or dementia because it opened conversation and was understood by elders who were willing to discuss their experiences. They described their forgetfulness as a consequence of aging. Acceptance and adaptation of forgetfulness were discussed by the Navajo elders. Consideration of rural caregiving as a cultural entity providing educational programs to build and promote resilience should be considered when working with American Indian (AI) communities. The AI population is aging rapidly, but cognitive aging can be considered a natural process associated with advancing years (IOM, 2015).

Building caregiver resilience served to co-create understanding and knowledge, and support resilience for Native elders and caregivers of persons with memory loss and cognitive decline. The project concluded with educating family members of the Navajo Nation Council on Aging/Navajo Area Agency on Aging (NNCOA/NAAA) resource available. The NAAA is located in Window Rock, AZ and serves to ensure that Navajo elders receive all available benefits and services of which they are entitled and to preserve their dignity and respect and cultural diversity. The NNCOA assists the NAAA in developing and coordinating community-based services for Navajo elders. Some chapter houses did have a flyer posted regarding this resource, yet the elder and their family were not aware of this resource. Part of the education was

to inform of their local resources. Additionally, an accepted proposal to the community partner to continue educational support for building resilience in future ANE Food Runs was accepted.

A more in-depth understanding of Navajo ancient wellness philosophies is needed to guide future health promotion education and further support resilience. Much can be learned from American Indians of the Navajo community and the way in which caregivers experience positive rewards from caregiving. The strong reciprocal relationships and overall enjoyment of elders in the Navajo communities observed during the food runs and give-away-circles was invaluable. Taking from this experience caregiving can be implemented in Western society's ways of caring for the caregiver and care recipients to nurture reciprocal relationships and build and promote resilience in aging and cognitive decline.

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