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Understanding Caregivers of Native Hawaiian Kūpuna with Age-Related Memory Loss on One Hawaiian Homestead

Adrienne Dillard, PhD, MSW, LSW, University of Hawaii at Manoa, Department of Native Hawaiian Health John A. Burns School of Medicine

B. Puni Kekauoha, Kula no na Po'e Hawaii

Corresponding Author: Adrienne Dillard, adillard@hawaii.edu

ABSTRACT

Purpose/Background: Understanding the concerns and challenges of caregivers of Native Hawaiian kūpuna or elders (age 55 years and older) with age-related memory loss conditions, specifically, Alzheimer's Disease and Related Dementia (ADRD), on one Hawaiian Homestead is the focus of this translational research study. The goal of this research is to identify factors affecting the safe and compassionate care for kūpuna preferring to age-in-place.

In Native Hawaiian communities, it is culturally appropriate to care and support kūpuna who wish to age-in-place. This study was conducted in Papakōlea, a Native Hawaiian Homestead community consisting of three subdivisions in the city of Honolulu, located on the island of O'ahu using a cultural safety praxis. The literature on caregiving in the context of ADRD indicates that caregivers often are concerned about the safety of their elders in the home and wonder if they are "doing enough" to care for their loved one. As a result of their historical struggles, residents of Papakōlea place an emphasis on supporting and caring for kūpuna who wish to age-in-place. However, families voiced concerns of not being equipped to provide their kūpuna quality care.

Materials & Methods: This research is grounded in Community-Based Participatory Research (CBPR) principles and utilizes a mixed methods strategy to assess the needs and concerns of caregivers of Papakōlea. The study focuses on identifying the needs, knowledge, attitudes, and resources that enable or disable caregiving with a view toward informing care within the designated homestead community. The quantitative arm of the study involved development and administration of a written survey eliciting sociodemographic characteristics, as well as, knowledge-attitudes-behaviors on caregiving. The qualitative arm of the study involved focus groups to clarify and extend information learned through survey data. Participants of the study were self-identified current and former caregivers, age 18 and older, experienced in caring for kūpuna with conditions associated with age-related memory loss (e.g., ADRD).

Results: Approximately 92% of participants identified as Native Hawaiian (n=155).

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38 Understanding Caregivers of Native Hawaiian Kūpuna with Age-Related Memory Loss on One Hawaiian Homestead
 Dillard and Kekauoha

Ages ranged from 18 to 82 years (M = 51.22, SD 16.347). The results indicate that current and former caregivers provide care primarily to their mothers 41% (n=48), fathers 11% (n=13) and grandparents 21% (n=25). The number of kūpuna diagnosed with ADRD was 48% (n=42), about 52% (n=49) believed they cared for someone with ADRD even though they have not received a diagnosis from a physician.

Caregivers identified the need for family conversations on advance health care directives before a medical emergency and respite support as primary concerns.

Discussion/Conclusion: This study focused on Native Hawaiians, a marginalized population and the need to provide relevant ADRD services. Findings are used to assist this homestead community in determining the types of resources and support essential to mitigate caregiver burnout while simultaneously providing services to enhance kūpuna care while using HILINA'I concepts to continue to build trust and cultural safety using a research praxis (figure 1). There are differences between homestead communities across the state in the expression of Hawaiian values and practices and degrees of community resilience.

Therefore, this study may not be representative of all homesteads statewide.

Table 1. Kupuna Relationship to Caregiver

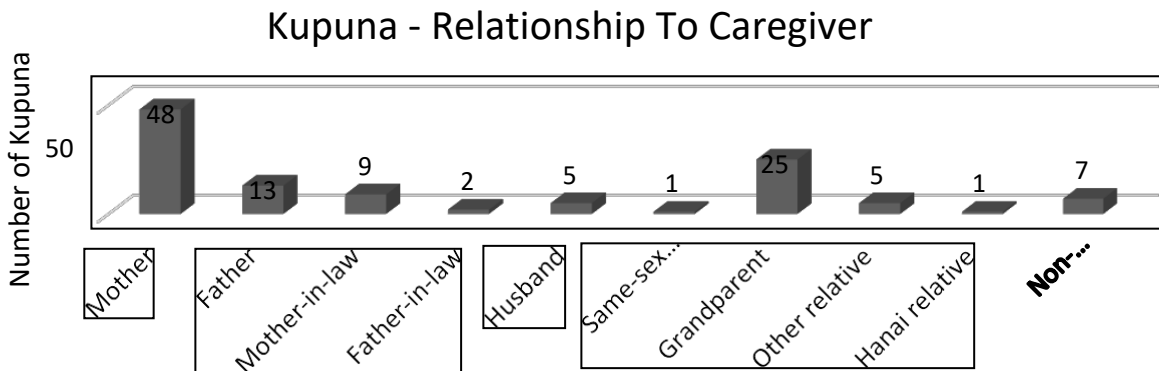


Figure 1. HILINA'I Cultural Safety Source: (Ka'opua, Tamang, Dillard, Kekauoha, 2017)

| “HILINA’I” | |
|--|--|
| Building Trust and Cultural Safety in Research Praxis | |
| H | Honor a community’s history of strength and resilience, vision for health-wellness, lifeways, and research needs and priorities. |
| I | Introspect on personal, professional, and organizational biases that may influence negative attributions of poor health outcomes in a community and among its members. |
| L | Learn community ways of knowing and transmitting what is known. Be open to learning from kia’i, kūpuna, traditional practitioners, and other community members. |
| I | Involve self in community activities, get to know community as more than a study site and to know residents as more than (potential) study participants. This may set the foundation for holistic and enduring relations with community and its members. |
| N | Nurture meaningful community participation in the research endeavor across the trajectory of a project—from needs assessment to intervention development, evaluation, and dissemination of findings. |
| A | Act to enhance research capacity of persons-in-community and of community as dynamic organization. Partner/mentor on specific research activities when possible, and know when to “release” research leadership to community members. |
| ‘I | Insurrect relationships of unequal power and control through culturally-grounded relationships and dialogic processes. |