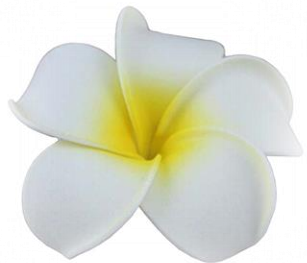




Understanding Caregivers of  
Native Hawaiian Kūpuna  
with Age-Related Memory Loss  
on One Hawaiian Homestead



NASW Conference  
October 4, 2018  
Adrienne Dillard, PhD, MSW, LSW



# Study Overview

This study addressed the needs of caregivers of Native Hawaiian kūpuna with memory loss or Alzheimer's Disease or Related Dementia (ADRD) in Papakōlea Hawaiian Homestead. The years that one can provide caregiving for a loved one with dementia-related conditions can lead to caregiver illness, depression, stress, and anxiety (Biegel & Schulz, 1999). This is a mixed methods, quantitative (mail survey) and qualitative (focus groups) study using a community based participatory research approach.

The survey instrument is a modification of existing surveys. Focus groups are with key informant interviews and current and former caregivers of Native Hawaiian kūpuna with memory loss to include ADRD. Papakōlea has benefitted from the CBPR approach in previous research. Thus, CBPR will be used for all methods of data collection, analyses, and dissemination, when possible (Ka'opua, Tamang, Dillard, & Kekauoha, 2017).

This study will assist the community in reaching goals of implementation of a culturally tailored intervention that will help to serve kūpuna with memory loss and their caregivers. In a dementia friendly community residents are dementia literate with an understanding of ADRD that helps to improve the quality of life for the caregiver and the person with ADRD (Dementia Friendly America, 2015).



Papakōlea, a Hawaiian homestead with the largest concentration of Native Hawaiians in urban Honolulu consists of the areas of Auwaiolimu, communities of: Papakōlea (1934); Kewalo (circa 1954), and Kalāwahine (2000), Hawaiian Homesteads on O'ahu island, (hereafter, referred to as Papakōlea) supported and participated in this research (Schachter, 2016).

Kewalo, Kalāwahine, and Papakōlea in central Honolulu on the island of O'ahu. It is located adjacent to the National Memorial Cemetery of the Pacific at Puowaina (Punchbowl) Crater at the base of the Ko'olau Mountain range.



On May 16, 1934, the Congress of the United States of America designated the areas of Auwaiolimu, Kewalo and Kalāwahine, known as Papakōlea, as Hawaiian Home Lands under the Hawaiian Homes Commission Act of 1920. Papakōlea covers 177 acres and is the only urban Hawaiian homestead in the city Honolulu, out of 36 homesteads in Hawai'i statewide.



Hawaiian Home Land areas are normally designated for construction before tenant selection occurs. Papakōlea is the only Hawaiian Home Lands area located in urban Honolulu, and where residents were “squatters” and fought for the land they occupied, to be included in the HHCA. This one of the reasons the reverence for the kūpuna of Papakōlea is in the cultural fabric of the community.



# HAWAIIAN HOMESTEAD

The land is held in federal trust that was established by the Hawaiian Homes Commission Act of 1921. The State of Hawai'i, Department of Hawaiian Home Lands, administers that “land trust,” providing initial 99-year residential leases to qualified native Hawaiians (The State of Hawai'i, 2005).

- Homestead land was intended for reparations for the overthrow of the Hawaiian Monarch and the loss of land during the Great Mahele of 1848.
- The HHCA was enacted on [July 9, 1921](#), as a rehabilitation program and is still in effect today. At the federal level, the Department of Interior has oversight of the HHCA and Department of Hawaiian Home Lands (DHHL).
- The HHCA reserves homestead land reserved for those who are of no less than 50 percent native Hawaiian ancestry...the vast majority of residents are of native Hawaiian or part-Hawaiian ancestry.
- Direct benefits to native Hawaiians in the form of 99-year residential, agricultural, or pastoral homestead leases for an aggregate term not to exceed 199 years at an annual rental of \$1 (The State of Hawai'i, 2005). Today, there are 36 homestead communities statewide.

# PAPAKŌLEA



Map of the Papakōlea Residential Communities DHHL 2009 Papakōlea Regional Plan.

# STATEMENT OF PROBLEM

Alzheimer's, is the most prevalent form of dementia in the U.S., Hawai'i, and of the kūpuna participating in Papakōlea Kawaihonaakealoha Program (Alzheimer's Association, 2015; Kawaihonaakealoha Report, 2016).

People with dementia, their families, and friends are affected on personal, emotional, financial, and social levels. A proper understanding of the societal costs of dementia, and how these have an impact on families, health, social care services, and governments causes a problem (Alzheimer's Association, 2010).

Because of the higher prevalence of cardiovascular disease, obesity, hypertension, and diabetes among Native Hawaiians this group would be more likely to have hospitalizations with a dementia diagnosis compared to other racial/ethnic populations (Sentell et al., 2015).

What we know about Native Hawaiian dementia caregivers on Hawaiian Homestead is limited. ADRD among Native Hawaiians is extremely understudied, it is not clear if these higher rates of patients hospitalized with dementia are related to higher underlying dementia risk (Sentell, 2015).

The # participants on Papakōlea Homestead Health Survey who indicated they had parents with ADRD or age-related dementia was 27, (25.9%), and 15 with a maternal grandparent, (14.4%) and 12 with a paternal grandparent (11.5%) (Homestead Health Survey, 2015).





# Papakōlea Top 5 Chronic Diseases (Kūpuna)

Hypertension, diabetes, and obesity are risk factors for dementia and are prevalent in Native Hawaiian kūpuna of Papakōlea as identified in surveys of 2008 and 2015. These conditions are among the top five chronic diseases in this population.

n=238

Top 5 Chronic Diseases “2008”	
Hypertension	58%
Arthritis	31%
Diabetes	26%
Cataracts	17%
Asthma	15%

\*Kawaihonaakealoha Kūpuna Report 2008

*Note: Kūpuna defined as age 55 and older.*

n=125

Top 5 Chronic Diseases “2015”	
Hypertension	54%
High Cholesterol	41%
Asthma	26%
Diabetes	23%
Arthritis	17%

\*Papakōlea Homestead Health Survey 2015



# Statement of the Problem (cont.)

- ❖ Caring for loved ones with memory loss can be extremely stressful as caregivers tend to put their lives on hold and may even experience illness due to stress themselves as they care for loved ones.
- ❖ Family caregivers of individuals with ADRD, often called the invisible second patients are critical to the quality of life of the care recipients.
- ❖ Despite the high prevalence of dementia, negative community attitudes and stigma towards dementia are still common (McCloskey et al., 2017). Individuals with ADRD experience multiple symptoms that change over a period of years.
- ❖ The pace at which symptoms advance from mild to moderate to severe varies from person to person (Alzheimer's Association, 2018).

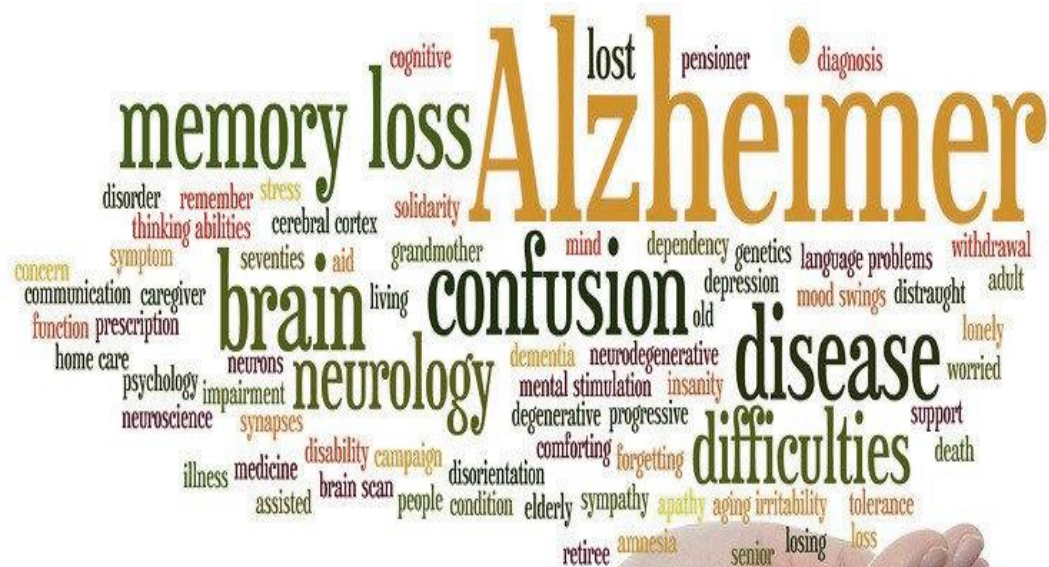


# Caregiver:

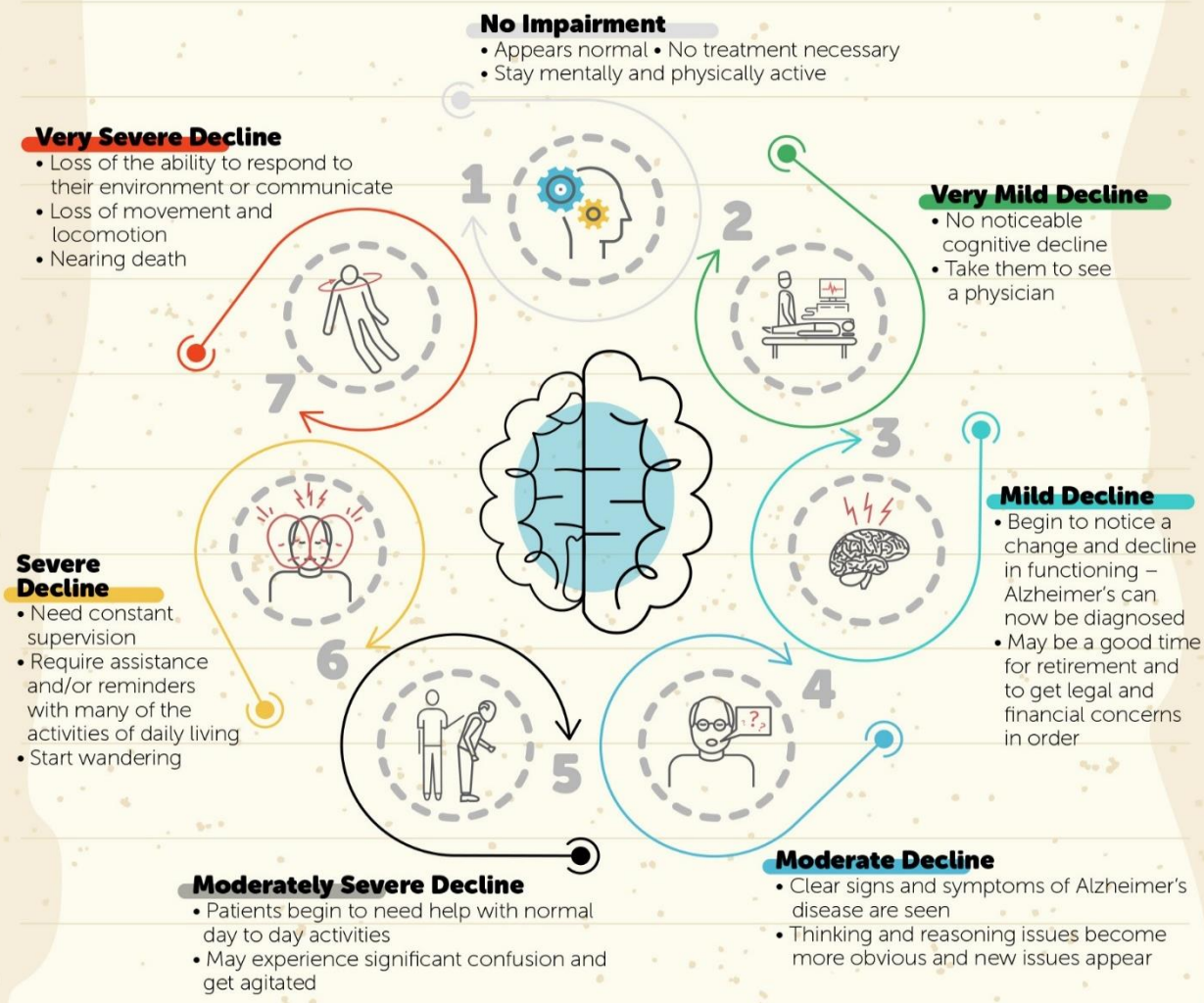
A caregiver is someone who provides care to a person in need of assistance with Activities of Daily Living, or everyday tasks such as self-care and personal hygiene.

- The three primary reasons caregivers provide care and assistance to a person with ADRD are:
  - the desire to keep a family member or friend at home (65%);
  - proximity to the person with dementia (48%); and
  - the caregiver's perceived obligation as a spouse or partner (38%). (Alzheimer's Association, 2010).
- Many caregivers feel that there are adverse reactions to the term dementia, and are concerned others would associate it with being 'demented.'
- Caregivers who find themselves *squeezed* in between caring for younger loved ones such as children, and their elder parents or other elder family members are the "*Sandwich Generation*" (Alzheimer's Association, 2016).

# Stages of Alzheimer's disease



## PROGRESSION OF ALZHEIMER'S DISEASE



Alzheimer's treatment and care are connected. Although there is no cure, there is a lot that can be done.



The treatment regimen that will be prescribed varies from person to person. Finding the appropriate treatment depends on the patient and any comorbid conditions that he or she may have.

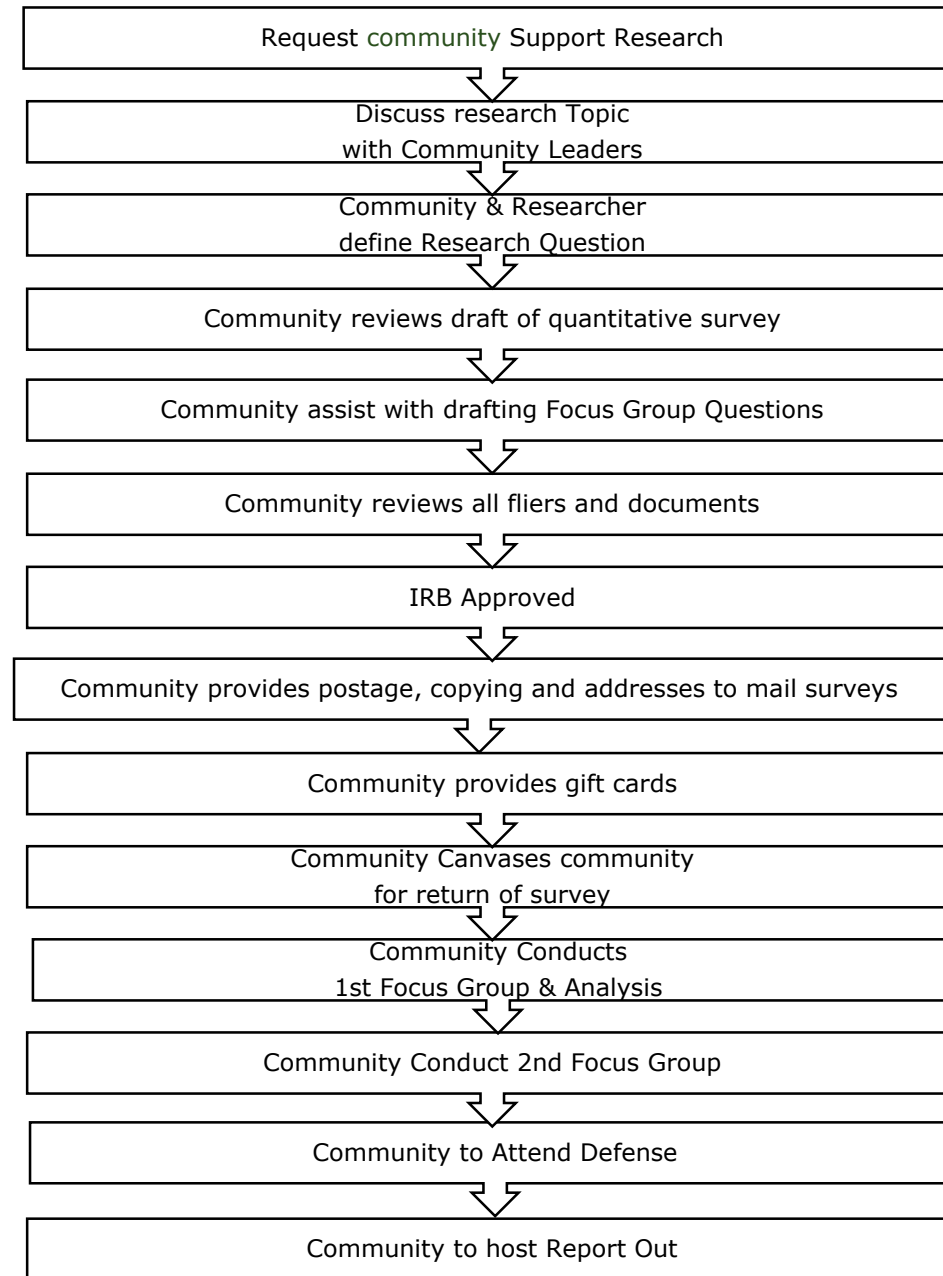
# Community Based participatory research

CBPR expands the potential for the translational sciences to develop, implement, and disseminate effective interventions across diverse communities through strategies to redress power imbalances; facilitate mutual benefit among the community and academic partners; and promote reciprocal knowledge translation, incorporating community theories into the research (Minkler and Duran, 2004).

The fundamental characteristics of CBPR are:

- (1) it is *participatory*;
- (2) it is co-operative, engaging community members and researchers in a *joint process* to which each contribute equally;
- (3) it is a *co-learning process*;
- (4) it involves systems development and local *capacity building*;
- (5) it is an *empowering process* through which participants can increase control over their lives; and,
- (6) it *achieves a balance* between research and action (Minkler & Wallerstein, 2008).

# CBPR PROCESS



# MIX METHODS STUDY

Mixed Methods using a CBPR process was thought to be what was most appropriate for the stage of caregiving that was believed to exist in community. Focus groups many times consists of the people most willing to engage and it was believed by conducting the quantitative study first respondents would get a better sense of what type of information they would be able to share during the focus groups. This brought those people most impacted by our study to engage.

- Data collection was sequential
- Level of data interaction was parallel
- No data set was given dominance over the other, both are equally important to understand the dynamics of aging for Papakōlea.
- Analysis of data was being conducted concurrently, there was an overlap, after the completion of focus groups, but preliminary findings were used to help frame questions for focus groups.
- When and how did synthesis and data integration occur, after the coding of data and content analysis, then the two were combined?
- There is iterative process that is ongoing because we continue to learn new things being in community.

# Methodologies

## Quantitative: Numeric Analysis

**Benefits:** Points out gender differences that exist between male and female caregivers, by sub-community, income, helps to identify knowledge, attitude, and resources (Chesney-Lind and Pasko, 2013).

**Limitations:** inability to determine why relationships between variables exist. Inability to determine perception (Chesney-Lind and Pasko, 2013).

**Examples:** surveys (on knowledge, attitudes, and resources. (Chesney-Lind and Pasko, 2013).

## Qualitative: Verbal Analysis

**Benefits:** Gives indigenous groups, whose voices have often been silenced, the opportunity to be heard in ways that are aligned with their long history of oral communication (Chesney-Lind and Pasko, 2013).

**Limitations:** Due to small sample sizes and non-randomized sampling procedures, findings are not likely to be generalizable. Can be criticized for being subjective(Chesney-Lind and Pasko, 2013).

**Examples:** Focus groups provide opportunities for marginalized groups, such as Native Hawaiians to articulate their needs which can lead to valuable insight about resources, interventions, and program development in the geographically bound community, such as Papakōlea.

# RESEARCH QUESTIONS



## Research Question

- 1

- How do caregivers of Native Hawaiian kūpuna dwelling in one homestead community perceive their needs as caregivers?

## Research Question

- 2

- What knowledge, attitudes, and resources enable their caregiving? Disable their caregiving?

## Research Question

- 3

- How does caregiver knowledge, attitudes, and resources affect the care of Native Hawaiian kūpuna with memory loss, including ADRD in one Hawaiian Homestead community?



*Aunty Angel & Chantal Kelihoomalū, MSW.*

# RESEARCH & DESIGN

A mixed methods strategy was used, with integration of Community-Based Participatory Research (CBPR) approaches. Quantitative (mail survey measure) and qualitative (key informant interviews, focus groups) methods were used sequentially.

## Phase 1

Quantitative

Mail survey (n=382)  
lessees  
Sampling (n=155)

## Qualitative

Focus Groups (FG) (key informants on resources and perception of needs; guide development of FG questions)

## Qualitative (cont.)

Focus 2 (2 groups -N=18) survey respondents on how caregiver knowledge, attitudes, and resources affect care.

Mail Survey

Data Analysis

Focus Groups  
Key Informants

Data Analysis

Focus Groups

Data Analysis

Dissemination  
of Findings



QUANTITATIVE

# Quantitative

- 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 survey questionnaire for the quantitative study was adapted from five other survey instruments: (1) Homestead Health Survey (2015), (2) UH-Kawaihonaakealoha Phase I demographics study (2007), the Dementia Friendly America Toolkit (2015); the Behavioral Risk Factor Surveillance Survey [BRFSS] Caregiver Module (2015); The Short Form of the Informant Questionnaire on Cognitive Decline in the Elderly (Short IQCODE, 1994)
- Surveys were mailed to 382 Hawaiian Homestead lessees in Papakōlea. The response rate of the mail survey was 40% surveys (n=155).
- The first 11 questions collected demographics on respondents, if they were not a current or former caregiver they could stop at questions 12 and return. There were 117 current or former caregivers of the 155 respondents.

## Consent and Instrumentation

## Data Collection

Surveys were mailed to 382 lessees of residences in Papakōlea (90%). The response rate of the initial mailing was 55% (n = 85). Snowball sampling was used to canvas community for another (n=70) 45% (N=155). Snowball sampling asks participants to identify others in their situation.

### University of Hawai'i Consent to Participate in Research

**Title of Study:** Understanding Caregivers of Native Hawaiian Kūpuna with Age-related Memory Loss on One Hawaiian Homestead

#### Informed Consent:

We are asking for your time to take part in this research because you are a resident of a Hawaiian Homestead community. About 400 people will be asked to be in the study. Before you decide whether you would like to participate, we want you to understand the purpose of this project, what you will be asked to do, and any possible benefits and risks. It is also important that you understand the following:

- Taking part in this research is **voluntary**. There will be no penalty or loss of benefits if you chose to not take part in this study.

#### Project Description:

The purpose of this study is assess the needs of caregivers of Native Hawaiian kūpuna with age-relaed memory loss or Alzheimer's Disease or Related Dementia (ADRD) on one Hawaiian Homestead using a community based participatory research approach. If you decide to take part in this project, you will be asked to fill out this survey packet. The survey questions are mainly multiple choice. Completing the survey will take approximately 45 minutes. You may choose to take breaks during the survey rather than completing it in one sitting. If you choose to participate in this study, you will be compensated for your time with a \$10 gift card to Foodland. Please return the survey by [due date which is 1 week from mail date] to receive the gift card. You will receive your \$10 gift card after mailing back your survey in the pre-addressed envelope with postage.

#### Benefits and Risks:

There will be no direct benefit to you for taking part in this project. The findings from this project may help create a better understanding of the health behaviors of Native Hawaiians residing on Hawaiian homestead lands. There is little risk to you in participating in this project however, disclosing information relating to caregiving may feel personal. Should you feel you need counseling, the social worker, Adrienne Dillard, is available at 808-520-8997 and can help you to find the appropriate counseling.

#### Confidentiality and Privacy:

We will not ask you for any personal information, such as your name or address during the survey. Your survey responses will not be linked to you or your address. Please do not include any personal information in your survey responses.

#### Returning the Survey:

If you decide to participate in this study, please place your survey in the pre-addressed and postmarked

## Papakōlea's Kupuna Caregiver Survey (Papakolea, Kewalo, and Kalawahine)

Aloha,

Mahalo for taking the time to participate in this community survey. Please complete the attached consent form and return with completed survey. If you plan to complete the survey on-line, please complete the consent form at link\_

#### 1. Email address \*

\_\_\_\_\_

#### 2. Are you a caregiver for a Kupuna of Papakolea?

Mark only one oval per row.

	Yes	No	If able	Not Sure
Primary Caregiver	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Secondary Caregiver	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide care only when asked	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide respite caregiving	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregiver with specific role, e.g. transportation to doctor or control finance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

#### 3. Are you Native Hawaiian?

Check all that apply.

- Yes  
 No

#### 4. How many kupuna does caregiver provide care?

Check all that apply.

- 1  
 2  
 3  
 4  
 5  
 Between 6 - 10?  
 More than 10?

# Coding for Analysis

Data Analysis  
conducted on  
SPSS ver 22.0  
2015

## CAREGIVING

14. Caregiver Role = nominal

Can have more than one role per person

1=Primary Caregiver

2=Secondary Caregiver

3=Provide care only when asked

4=Provide respite caregiving

5=Caregiver w/specific role

15. Enjoyment of Caregiving = ordinal

Count by level of enjoyment, level of enjoyment by dementia vs other conditions

Scale = 6 Don't Know 5 Very High 4 High 3 Moderate 2 Low 1 Do Not Enjoy

***30 greatest enjoyment 36 greatest doubt 0 least enjoyment***

Time

Feeding

Medication Mgmt

Companionship

Personal Needs

Finances

16. Reside With Kupuna = nominal

1 = Yes, Full Time

2 = Yes, Part-Time

3= No

17. Length of Caregiving = nominal

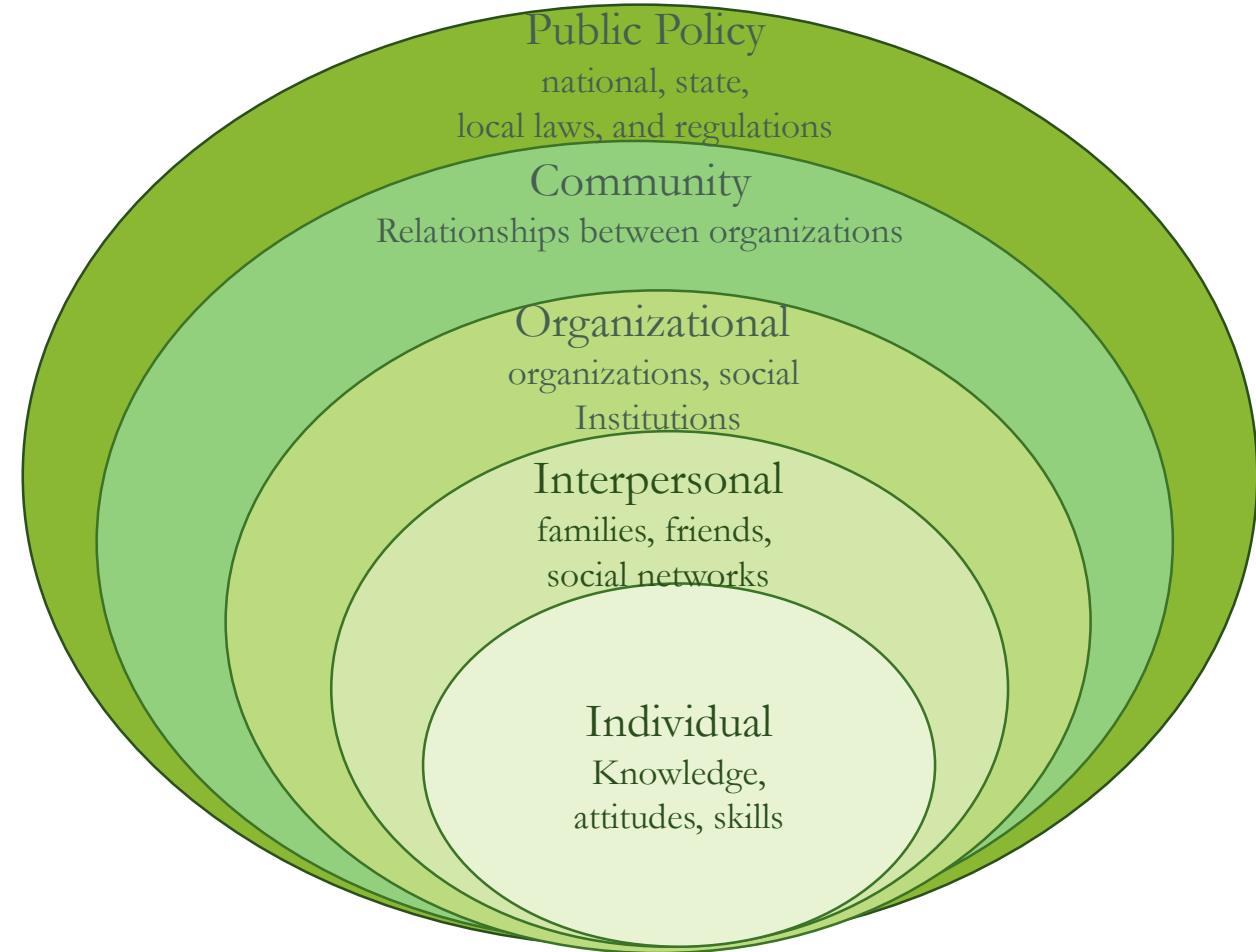
**QUALITATIVE**



# SOCIO-ECOLOGICAL MODEL



The socio-ecological model combines the ecological and system theory models is used to focus on either the individual caregiver or kūpuna, his or her situation, and the effect of illness on the system and environment.



# QUALITATIVE

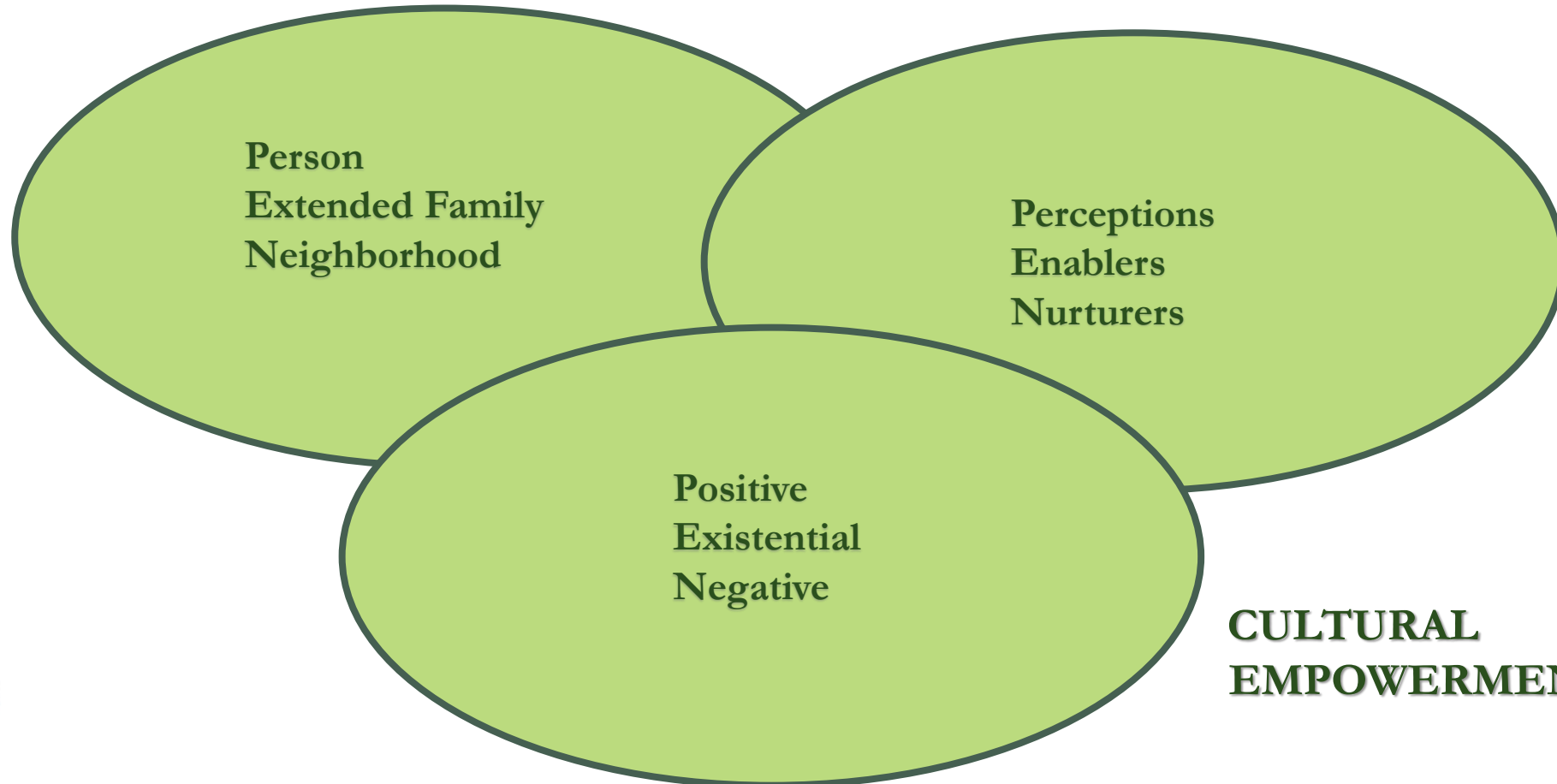
- ❖ The qualitative arm of the study involved focus groups and was intended to clarify and extend information learned through survey data.
- ❖ Specifically, focus groups elicited participants' caregiving experience in the context of ADRD.
- ❖ Our mixed methods design allows us to infer with some certainty the causal factors at play in increasing community support for this population.
- ❖ Two 90 minutes focus groups were held on two consecutive evenings in the Papakōlea Community Center Library.
- ❖ Group one was comprised of 56% of the participants (n=10), while group two was a homogenous male group comprised of 44% (n=8).
- ❖ Total focus group participants equaled 18 adults.

# PEN-3 MODEL



**CULTURAL IDENTITY**

**RELATIONSHIPS and  
EXPECTATIONS**



**CULTURAL  
EMPOWERMENT**





# QUALITATIVE

Papakōlea residents that (a) self-identify as a current or former caregiver of a Native Hawaiian kūpuna with memory loss, e.g., ADRD or other chronic disease (b) be  $\geq 18$  years at the time of the study, (c) express interest in participating. Two focus groups of eight to ten individuals were held. (Maximum n=18). Participants were encouraged to reply to each question but were apprised of their right not to respond or to leave at any time without consequence.

## Approach

An inductive methodology was selected as part of this study to explore the perceptions, knowledge, attitudes, and challenges of community caregivers of kūpuna with ADRD and other chronic disease. The use of focus groups allow the opportunity for the “kukakuka” style of sharing information most comfortable to community members (Browne, et. al., 2014).

## Data Collection

Primary strategies: Open ended questions were asked by facilitator to guide the conversation regarding knowledge, and past, present caregiver experiences inclusive of cultural knowledge & practices. The focus group methodology was employed because it is consistent with the tradition of Native Hawaiians who prefer to share their experiences orally and face-to-face (versus surveys or telephone interviews), allowing them to judge the researcher’s intent and trustworthiness as information is shared. The focus group questions were constructed to answer the three research questions and follow-up on previous focus group conversations.

## Data Analysis

Three Reviewers extracted themes based on (1) their mention in the focus group, (2) their elaboration or endorsement by other members in the group, and (3) their mention in both of focus groups. After the reviewers identified themes, they met as a group along with the focus group facilitator and co-facilitator to discuss the identified themes and their placement within the four categories of greatest interests that aligned with quantitative data collected . Themes that were similar were aggregated into a single representative theme.

# RESULTS

# CAREGIVER & KŪPUNA CHARACTERISTICS

Table 1. Caregivers Age

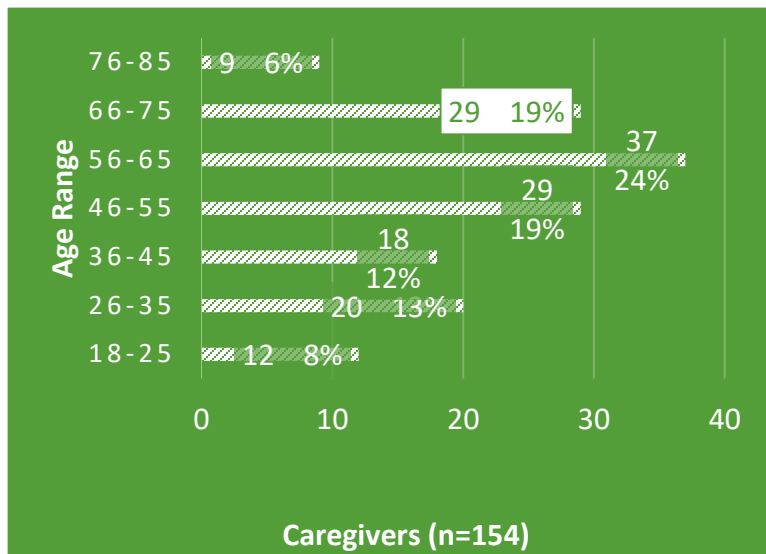


Table 2. Caregivers Ethnicity

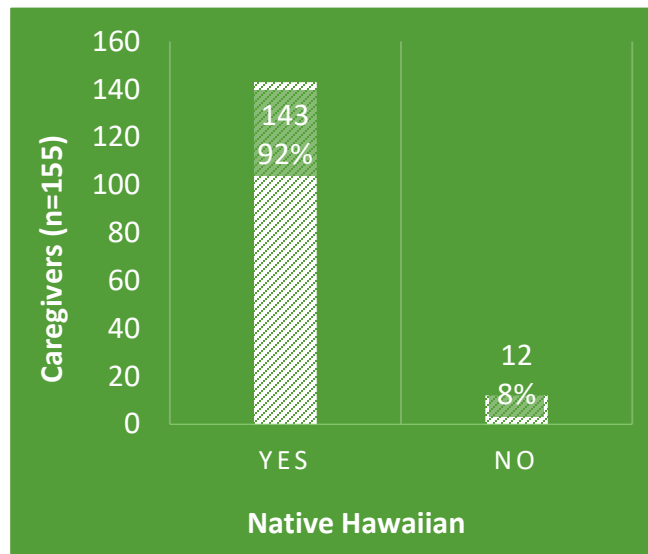


Table 3. Caregivers Gender



Table 4. Kūpuna Age

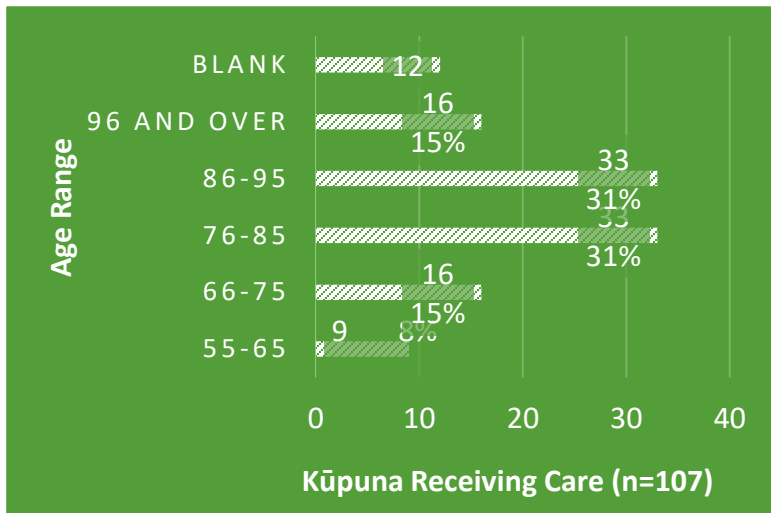


Table 5. Kūpuna Ethnicity

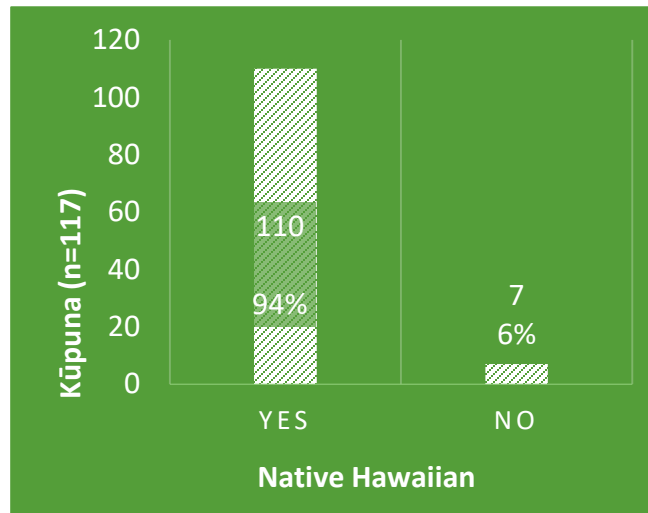
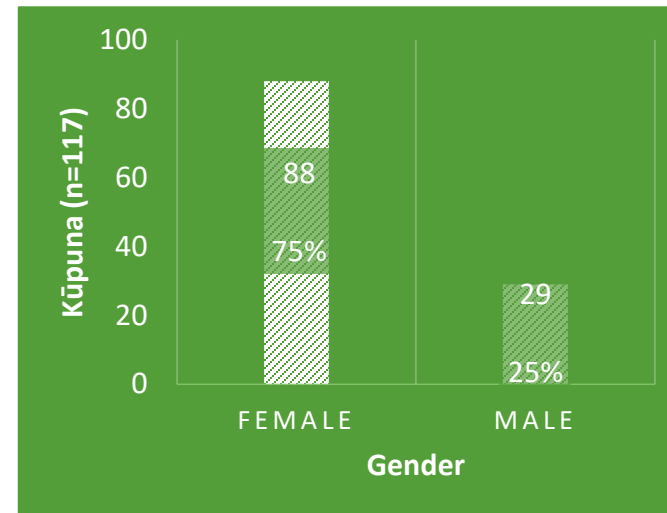


Table 6. Kūpuna Gender



# Research Question 1

How do caregivers of Native Hawaiian kūpuna dwelling on one homestead community perceive their concerns as caregivers?

Table 7. Services Needed

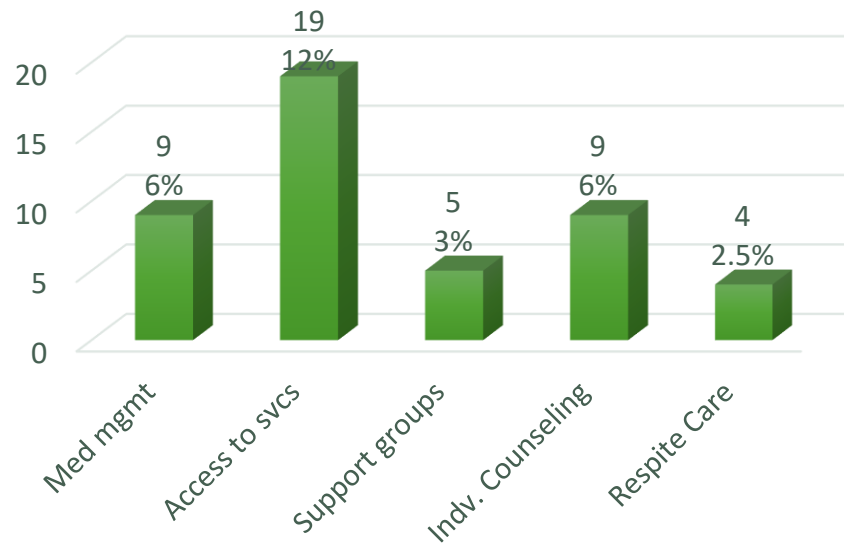
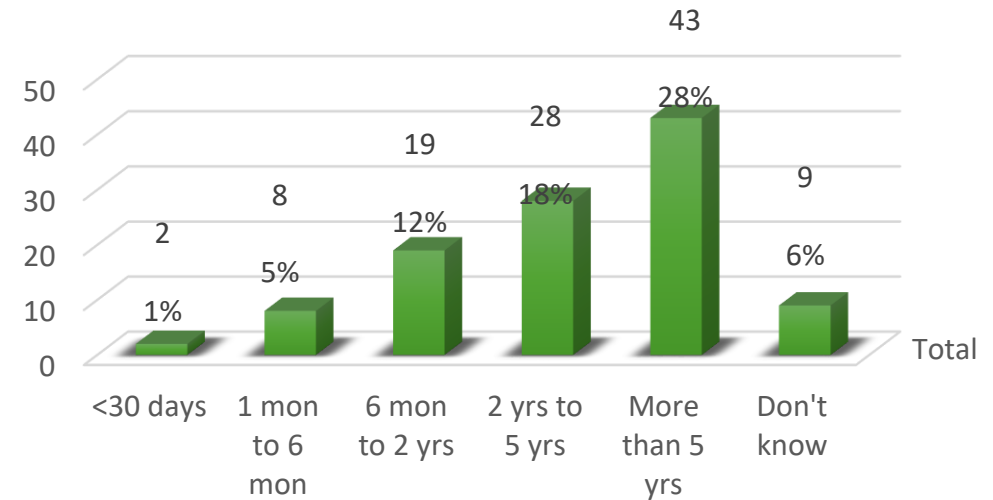


Table 8. Length of Caregiving



# Research Question 2

- What knowledge, attitudes, and resources enable their caregiving? Disable their caregiving?

Table 9. Personal benefit from dementia training?

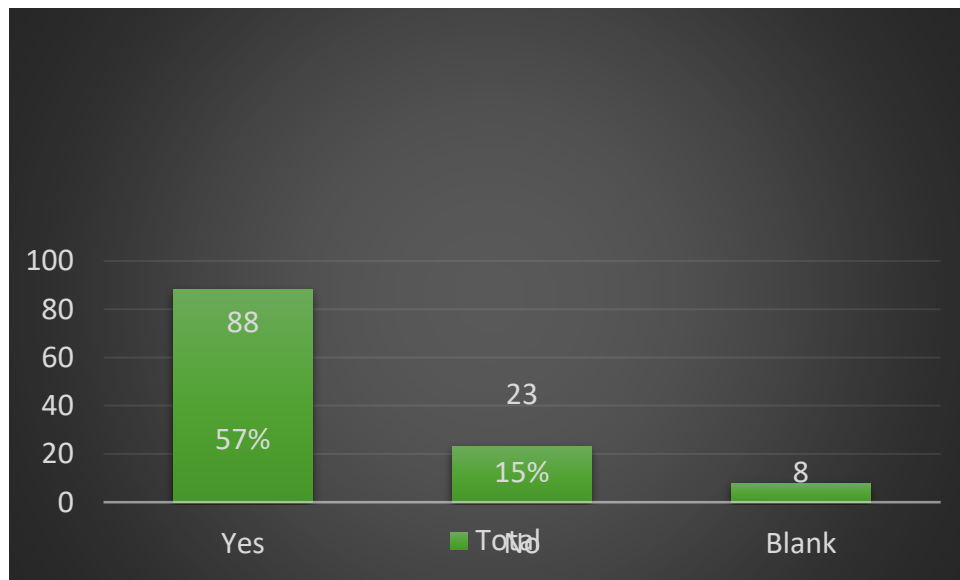
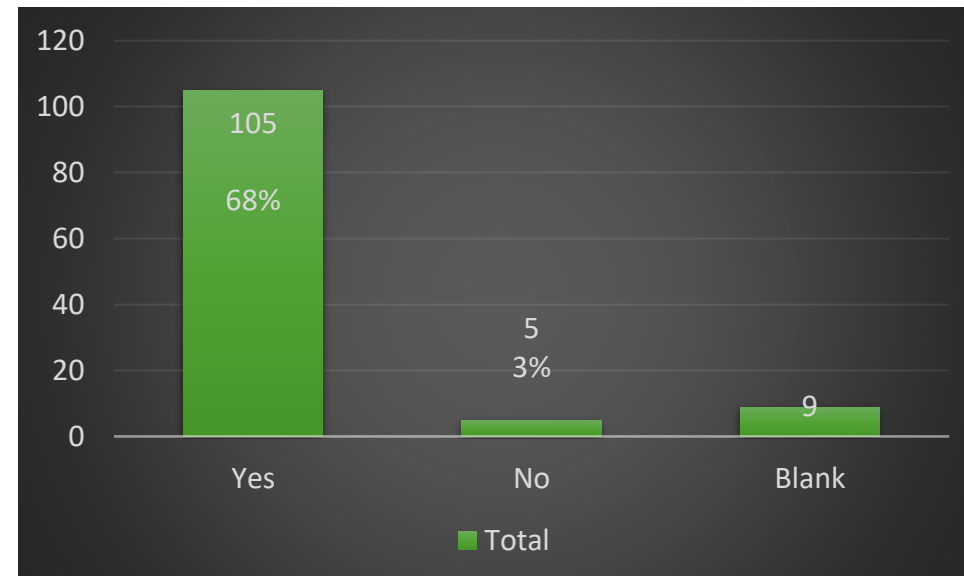


Table 10. Papakōlea families benefit from dementia training?



# Research Question 3

- How does caregiver knowledge, attitudes, and resources affect the care of Native Hawaiian kūpuna with memory loss, including ADRD?

Table 11. Do you feel Kūpuna has undiagnosed dementia?

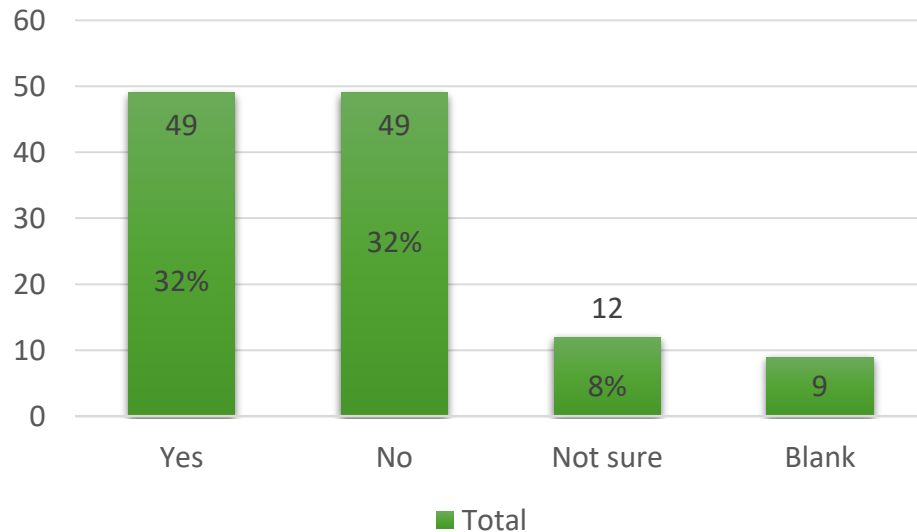
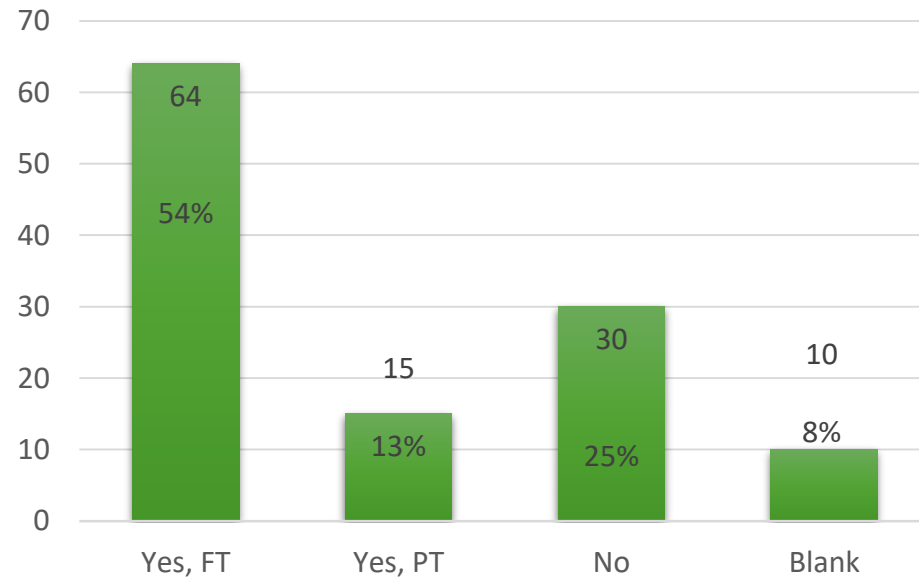


Table 12. Reside with Kūpuna?



# RESULTS

- ✓ Approximately 92% of participants identified as Native Hawaiian
- ✓ Age of caregivers ranged from 18 to 82 years ( $M = 51.22$ ,  $SD 16.347$ ).
- ✓ 48% of the kūpuna have been diagnosed with an ADRD (n=42)
- ✓ 54% (n=49) believed that they cared for someone with an ADRD, not diagnosed by their physician.
- ✓ care primarily to their mothers 41% (n=48), fathers 11% (n=13) and grandparents 21% (n=25).

Table 13. Care enjoyment.

	Coefficient	Standard Error	Odds Ratio	95% CI Lower Limit	95% CI Upper Limit	p-value
(Intercept)	-0.026	1.0556	0.9743	0.123	7.713	0.98
<b>Length of Time</b>	Reference: < 2 years					
2 years < 5 years	1.1937	0.868	3.2993	0.602	18.082	0.169
More than 5 years	-0.8183	0.6965	0.4412	0.113	1.728	0.24
<b>Enjoyment</b>	0.0017	0.0389	1.0017	0.928	1.081	0.965
<b>Care Provided</b>	Reference: No					
Personal Care	1.985	0.8523	7.2789	1.369	38.688	0.02
Household Tasks	-2.0315	0.8335	0.1311	0.026	0.672	0.015
Outside Services	-0.0805	1.0026	0.9226	0.129	6.584	0.936
Access to Services	-0.31	0.7699	0.7335	0.162	3.317	0.687
Support Group	-0.3278	1.0513	0.7205	0.092	5.655	0.755
Arranging Respite	2.7865	1.3941	16.2238	1.056	249.348	0.046

Providing personal care for kūpuna (such as giving medications, feeding, dressing, or bathing) in the last 30 days has 7.3 times higher odds of kūpuna having been diagnosed with dementia compared to caregivers who didn't provide personal care in the last 30 days.

Providing household tasks for kūpuna (such as cleaning, managing money, or preparing meals) in the last 30 days has 87% ( $1 - 0.13 = 0.87$ ) lower odds of kūpuna having been diagnosed with dementia compared to caregivers who didn't provide household tasks care in the last 30 days.



## CAREGIVER FOCUS GROUPS CHARACTERISTICS

Table 13. Focus Groups

Combined sample (N = 18)	Group 1	Group 2	Focus Groups
<b>Ethnicity</b>	<b>%</b>	<b>%</b>	<b>%</b>
Hawaiian	10 (55.0)	8 (45.0)	18 (100.0)
<b>Gender</b>			
Female	9 (90.0)	0 (00.00)	9 (50.0)
Male	1 (10.0)	8 (100.0)	9 (50.0)
<b>Community</b>			
Papakōlea	4(40.0)	3 (37.5)	7 (38.8)
Kewalo	2(20.0)	2 (25.0)	4 (22.2)
Kalawāhine	2(20.0)	2 (25.0)	4 (22.2)
Other	2(20.0)	1 (12.5)	3 (16.6)
<b>Caregiver status</b>			
Current Caregiver	7(70.0)	5 (62.5)	12 (66.6)
Former Caregiver	3(30.0)	3 (37.5)	6 (33.4)
Caregiver 1	8(80.0)	6 (75.0)	14 (77.8)
Caregiver 2 or more	2(20.0)	2 (25.0)	4 (22.2)
Kūpuna w/Alzheimer's	7(70.0)	3 (37.5)	10 (55.5)
Kūpuna w/Chronic Disease	3(30.0)	5 (62.5)	8 (44.5)

Data are *n* (%) or means ± S.D.



Themes of caregivers COMMUNITY SUPPORT  
Focus Groups N=18

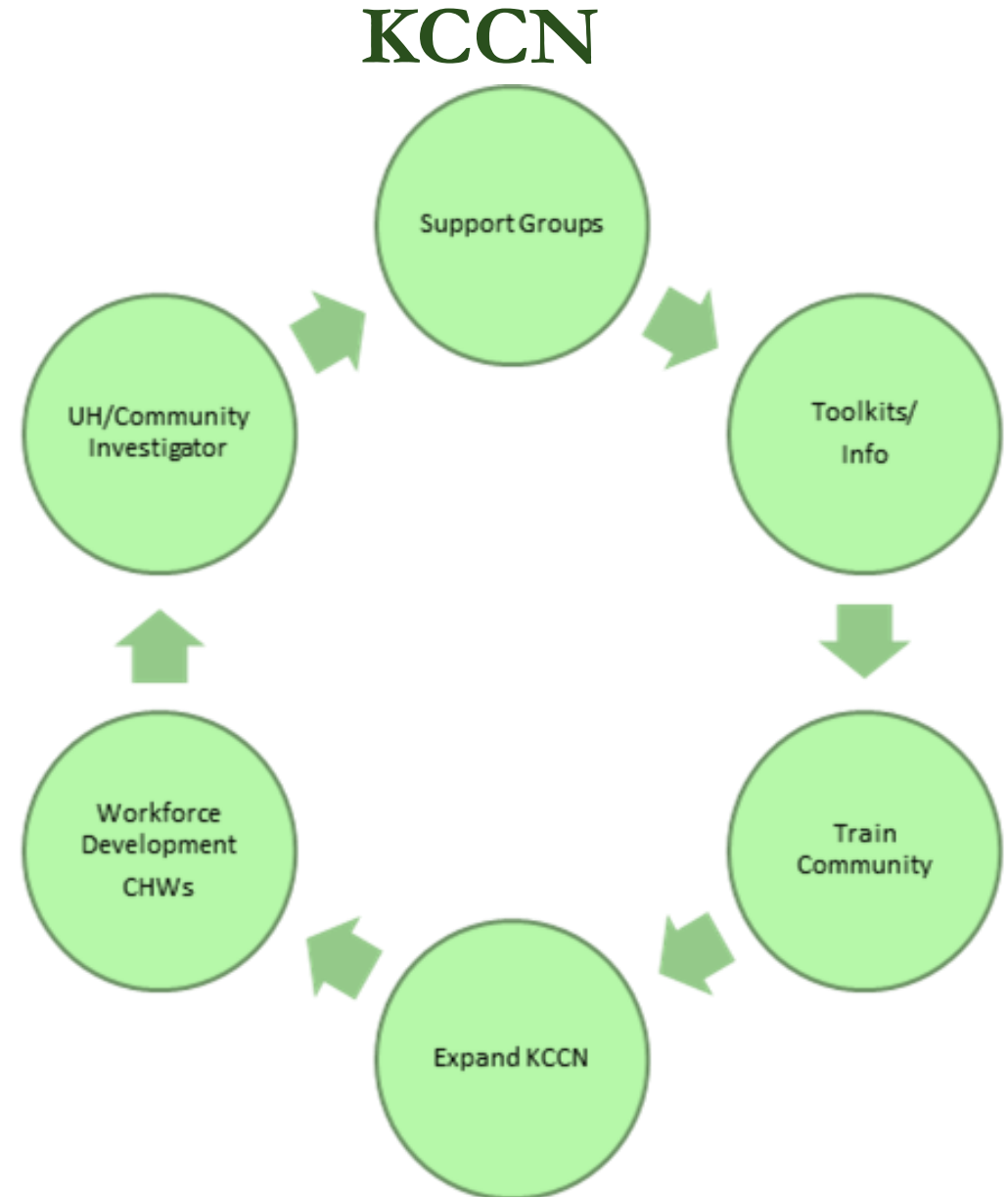
Domains and themes	Representative quotes
<b>COMMUNICATION</b>	“...Would come to a support group for men and women and willing to help recruit people from the community who need to be part of the conversation...” need to plan ahead of time and start the conversation early
<b>SUPPORT GROUPS</b>	“Would come to a <u>community only</u> , mixed M/F support group” Need to be able to talk story with others. Many going through the same thing... Learn as you go when caregiving...”
<b>COMMUNITY PUBLIC SERVICE ANNOUNCEMENTS</b>	“...empower families to have the conversation earlier, so much pilikia, and need education tools in the community so kūpuna can make up on mind and plan...”
<b>COMMUNITY KULEANA</b>	“...community should know who is homebound and needs respite...be proactive to determine people that people know...give tips and advice... everyone has to react...disaster recovery...”Getting access to services - where to start? Loss with new residents
<b>HEALTH/DEMENTIA LITERACY</b>	“...comforting to know you are not the only one going through...learned a lot tonight...” Informational supports – need One stop, overwhelming go to office browsers, looking for services, navigators
<b>NEED COMMUNITY SUPPORT</b>	“...Outside services - how to get access? Community helps with services...No longer about “me,” about “us.” Respect...”
<b>GENDER ROLES</b>	Women tend to be natural caregivers; Men have trouble communicating, Men are in denial, Kūpuna gets angry, cuss - hard to help, Hard to provide feminine care for both CG and kūpuna - especially for Mom Role reversal - kūpuna raised them, now CG is taking care of kūpuna
<b>NEED TO COMMUNICATE</b>	“...Brothers and sisters - everyone must step up and pitch in...” “Kūpuna still need interactions/ socialization. Need a checklist to keep up with the opportunities as you learn about it – learned from someone about VA benefits was able to get Dad hearing aid that is hard to get...”
<b>RESPIRE/SELF CARE</b>	“...Self-care - have to take care of self to take better care of loved one...” CG is working a full-time Tough job - work all day, go home, then work all night”...Help each other out...need support group, mental & physical respite/support networks...share information

# Papakōlea Kūpuna Community Care Network Excursion November 2017



# RECOMMENDATIONS

- ❑ Develop a Kūpuna Community Network which functions as a “one stop...”
- ❑ Explore means to ensure compensation for family caregivers, including but not limited to health insurance re-imburement.
- ❑ Explore means to ensure Community Health Workers trained and employed in community
- ❑ Involve community stakeholders in designing the intervention process.
- ❑ Training for Dementia Friendly Community



# Recommendations / Conclusions:

- The current executive and legislative administration in Washington; DC threatens, defacto to eliminate health coverage for the most vulnerable populations, there are policy implications nationally that make it essential that health equity become at the forefront of social welfare conversation and policy talking points.
- This study highlights the needs of Native Hawaiian caregivers of a kūpuna with dementia needing and healthcare coverage 1) to adequately meet the needs of kūpuna presenting signs of memory loss needing home care coverage and 2) to alleviate stress and burnout of primary and supporting caregivers with the implementation of adequate family leave when necessary. Health disparities are preventable differences in the burden of disease, injury, violence, or in opportunities to achieve optimal health as experienced by socially disadvantaged racial, ethnic, and other population groups, and communities (Centers for Disease Control and Prevention, 2013).
- This research has determined there is a need for a culturally tailored interventions and when the community has the capacity and readiness to participate in programs such as the DFA network. Membership in the network provides tools to support engaging the caregivers and kūpuna of the Hawaiian homestead community in understanding what is needed to address the growing need of resources and additional support for family caregivers.

# IMPLICATIONS FOR SOCIAL WORK/SOCIAL WELFARE

- ❑ Findings from this study compel further research:
  - ✓ on ADRD caregivers.
  - ✓ caregivers of other conditions
  - ✓ policy that address family leave
  - ✓ benefits of the elderly
  - ✓ changing the structure of benefits for the elderly
  - ✓ Social Security as an entitlement under the current administration
- ❑ to adequately meet the needs of kūpuna presenting signs of memory loss needing home care coverage
- ❑ to alleviate stress and burnout of primary and supporting caregivers
- ❑ implementation of adequate family leave when necessary

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MAHALO





QUESTIONS????

