

Listening to the Voices of Nā Kūpuna and ‘Ohana Caregivers in Hawai‘i:

Discussions on Aging, Health, and Well-Being

December 2011

**Prepared by:
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**Hā Kūpuna: National Resource Center
for Native Hawaiian Elders**

Myron B. Thompson School of Social Work
University of Hawai‘i at Mānoa

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Executive Summary

Promoting health and well-being of nā kūpuna (elders)* involves understanding the long-term needs and cultural preferences of elders and their family members. Hā Kūpuna: National Resource Center for Native Hawaiian Elders (Hā Kūpuna), conducted a series of listening meetings to explore, better identify, and understand the needs and preferences for long-term care supports and services among groups of Native Hawaiian elders and caregivers on the islands of Molokaʻi, Hawaiʻi, Kauaʻi and Oʻahu. Listening meetings such as these, which record and describe the needs of kūpuna and family caregivers “in their own words” and in their own communities, can provide important information to policy makers, legislators, and administrators. We engaged elders and family caregivers in focus groups to solicit answers to a series of questions on their personal experiences with aging, care giving, and service preference and use. Hā Kūpuna is located at the University of Hawaiʻi at Mānoa within the Myron B. Thompson School of Social Work.

This listening study was conducted for several reasons. First, increasing life expectancies in Hawaiʻi has led to a dramatically different demographic state profile. Nearly 231,000 Hawaiʻi residents are 65 years of age and over (14.5% of the state’s population), and projections estimate that the elder population will increase between 2000 and 2030 by an impressive 70%—over three times faster than the general population (U.S. Bureau of the Census, 2010). Second, Hawaiʻi residents can boast about having the greatest longevity of all 50 states, but not all of our citizens live equally as long or as well. Native Hawaiians have a life expectancy shorter than most other ethnic groups of the state (Braun, Mokuau, & Browne, 2010). Third, longevity is a success story, but also can lead to increased social, health, and financial vulnerabilities for elders and their family. Fourth, most elders in Hawaiʻi continue to live in the community outside of institutions, relying on families and services to keep them healthy—and they want this to continue. And, finally, the needs of elders and families with regards to their long-term care service and support needs and preferences are relatively unknown. Reports from ALU LIKE and the State of Hawaiʻi Executive Office on Aging (EOA) have found that nearly 1 out of 6 adults are caregivers to older adults, but also acknowledged the very limited knowledge we have about the needs of family caregivers (ALU LIKE, 2005; EOA, 2006).

Established in September 2006 with funds from the Administration on Aging in the US Department of Health and Human Services, Hā Kūpuna aims to investigate the needs of older adults and their caregivers in this community, and to identify the role of culture in providing this care. It is our hope that the knowledge generated by this study can help to advance appropriate programs and policy related to aging and eldercare and to help improve care available to elders and their family caregivers.

A total of 48 individuals participated in this study, including 24 kūpuna and 24 ʻohana (family) caregivers. Data were solicited through six 90-minute roundtable discussions held on the islands of Molokaʻi, Hawaiʻi, Kauaʻi, and Oʻahu. The discussions were transcribed and analyzed for themes.

The data revealed a number of major themes and subthemes related to aging, health, caregiving and well-being. We found that, for the most part, both kūpuna and ʻohana caregivers discussed similar

*The Hawaiian word for elders is kūpuna. Kūpuna with the diacritical mark (macron) over the ū indicates more than one elder, and without the macron (kupuna) indicates a single elder.

concerns and needs. These major themes included: 1) financial worries and concerns; 2) health and caregiving concerns; 3) barriers to well-being; 4) the role of kūpuna in eldercare and in Native Hawaiian culture and cultural preservation; and 5) care/service preferences.

Financial Worries and Concerns. The high costs of food, healthcare, housing, and services were topics of major concern. Kūpuna worried about becoming a burden to their families, while families worried about providing the necessary care when health and long-term care costs were high and when caregiving conflicted with employment and other responsibilities. Elders and their caregivers hope that all nā kūpuna can “age in place,” but realized that they needed financial and service supports from a mix of family members and government providers to do so.

Health and Care giving Concerns. Elders and their caregivers discussed the fluidity of the aging experience and the caregiver role, and the need for constant adjustment of both parties to accommodate changes. Participants in all groups readily discussed the increasing health needs of nā kūpuna with age that result in increased family expectations to provide care giving. Kūpuna hoped to age-in-place, and yet were not knowledgeable about the health risks that are more common in Native Hawaiian elders compared to their non-native aged counterparts in Hawai‘i. This was also true for ‘ohana caregivers, and has implications for health promotion, prevention, education, and treatment. Services of the Native Hawaiian Health Care System and ALU LIKE were specifically mentioned as helping nā kūpuna remain at home. More specifically, nā kūpuna concerns centered on maintaining a healthy diet, having an adequate income, receiving respect from family members and service providers, and the accessibility for specific support services. Families also voiced concerns around the financial burden of care giving, barriers to accessing services (including nā kūpuna who are reluctant to ask for help), and limited ‘ohana care giving education and support services. Families sought help to do the tasks required of them, and yet were troubled by non-responsive organizations (see the following comment). The one-stop shop on the Island of Hawai‘i, administered by the Hawai‘i County Office of Aging, was seen as a way to increase access to information and services. Three services were identified as most important in helping ‘ohana keep elders at home—respite, transportation, and family education.

Barriers to Well-Being. A number of federal, state, and private agencies work to provide elder and family support services to promote elder independence, support family in care giving tasks, and potentially delay institutionalization. However, numerous participants voiced their frustration with what were perceived as barriers to accessing services provided by these agencies and organizations. These included agency/organizational financial eligibility rules and regulations, staff not properly trained to work with nā kūpuna (i.e., disrespectful staff, the importance of humility or ha‘aha‘a), and intrusive admission procedures. Nā kūpuna discussed how rules and regulations impact Native Hawaiian elders more than elders in other ethnic groups. For example, nā kūpuna are often unaware that they are listed as landowners on deeds, and this land ownership makes them ineligible for some services (e.g., Medicaid/Quest). Family caregivers also discussed another barrier to care—the reluctance of an elder to seek help when needed.

Role of Kūpuna in Eldercare and in Hawaiian Culture and Cultural Preservation. Woven into the fabric of every listening session were cultural issues. Although participants believed that aging was generally universal, there were in fact numerous comments and suggestions related to eldercare in terms of culture and cultural preservation. Among discussion points were: the kuleana (responsibility) of the family in providing care to nā kūpuna; elders’ concerns about becoming a family burden; the importance of prayer and spirituality in providing support to nā kūpuna and caregivers; the

role of nā kūpuna in the ‘ohana and in Hawaiian culture (cultural preservation); and the importance of respect and sensitivity to privacy issues in elder and ‘ohana communication. Cultural issues also were expressed in preferences for how the focus groups should be conducted, for example the use of pule wehe (prayer) to begin listening sessions. These points have implications for the design, delivery, and access to services, as well as for research.

Preferred Services. Through their comments, elders and caregivers identified those services that they would like to see more available. These included caregiver education and support, respite, and transportation. They also want to see staff education to increase sensitivity to Native Hawaiian issues, aging issues, and care giving concerns. Organizations such as Hawai‘i’s Executive Office on Aging and the Native Hawaiian Health Care Systems should review their own service mix to determine if kūpuna and ‘ohana needs are in fact being met. With regards to staff education and training, universities may offer coursework in aging, but many professionals and paraprofessionals in the field remain untrained. This is especially true in the area of cultural competence and aging.

Recommendations:

Given these findings, we recommend that:

- Kūpuna and ‘ohana caregivers have increased access to financial, social, and other supports and resources;
- Greater attention be focused on promoting healthy aging and aging-in-place especially for kūpuna;
- Federal, state, and private sector organizations review their policies and practices for potential barriers to services delivery and data collection needs and methods;
- Agency personnel be provided education, training, and supervision on how to provide skilled and respectful care to kūpuna and their ‘ohana;
- Services identified as needed most by kūpuna and their caregivers be funded, available and delivered in a culturally-informed manner (For a population with a generally poor health profile, barriers to care should be unacceptable); and
- All organizations that work with older adults and families should be informed of and adhere to cultural and linguistic standards for cultural competence, and commit themselves to educating their staff and insisting on respectful care for all elders. Culturally informed practices and policies promote responsive care that can impact service eligibility, access, and utilization.

Given the small sample size and limited generalizability of this study, we also recommend that continued study be conducted to strengthen our understanding of the relationship between culture, race and ethnicity, aging, and service program design and delivery mechanisms.

Introduction

Hā Kūpuna (HK), the National Resource Center for Native Hawaiian Elders, located in the Myron B. Thompson School of Social Work (MBTSSW) at the University of Hawai'i at Mānoa, was established in September 2006 with funding from the Administration on Aging, US Department of Health and Human Services. It is the newest of three national resource centers for native elders, joining the National Resource Center on Native American Aging at the University of North Dakota and the National Resource Center for American Indian, Alaska Native, and Native Hawaiian Elders at the University of Alaska-Anchorage. Drs. Noreen Mokuau, Colette Browne, and Kathryn Braun lead Hā Kūpuna.

The **mission** of Hā Kūpuna is to assure parity of life expectancy and good health among the state's growing number of older Native Hawaiians comparable with other older Americans. Its **goal** is to improve access to and delivery of services to all elders, with special focus on Native Hawaiian elders and their caregivers, through the development and dissemination of knowledge around health and long-term care. Hā Kūpuna is working to achieve this goal by building a national knowledge base on Native Hawaiian elders and their caregivers focused on long-term care needs, preferences, and patterns. Hā Kūpuna strives to enhance the community's knowledge of long-term care through the dissemination of research and the provision of technical assistance and training. This listening study aimed to assist all collaborative partners to better understand how to identify and meet the needs of both kūpuna and caregivers. This exploratory study is part of a larger statewide needs assessment of elder and family needs in long-term care conducted by the staff of Hā Kūpuna (See Braun et al, 2010, Browne, Mokuau, & Braun, 2008).

For this study, we convened and conducted six roundtable groups attended by 48 Native Hawaiian elders and caregivers who reside in the state of Hawai'i. We used established focus group methods to identify the needs of elders and caregivers around health, long-term care and well-being. Findings can help communities with caregiver needs assessment and strategic/program planning, encouraging more targeted interventions to serve both nā kūpuna and their 'ohana caregivers.

Problem Statement

According to the 2010 US Census, 1,225,295 of the nation's citizens claim Native Hawaiian and Other Pacific Islander (NHOPI) ancestry, Alone or in Combination (.02% of the country's population). NHOPI alone account for 540,103 of this number while NHOPI in combination account for 685,182 persons. From 2000 to 2010, there was a 35.4% reported increase in these numbers (U.S. Census, 2010). Hawai'i is home to 60% of Native Hawaiians, or about 136,031 Native Hawaiians.

There are approximately 260,000 older adults (60+) residing in Hawai'i, representing 14.5% of the state's 1,360,000 total population. About 36,000 of these older adults are Native Hawaiians. Compared to other ethnic groups in the State of Hawai'i, Native Hawaiian elders experience significant disparities in health, such as shorter life expectancy and higher rates of disability due to chronic diseases like heart disease, cancer, and diabetes. Associated with the greater burden of disability is the increased likelihood that the kūpuna lives with family, and yet the services of a paid caregiver are seldom used (ALU LIKE, 2005). The low utilization of services for nā kūpuna may result from unique

socioeconomic, geographic, and cultural characteristics of Native Hawaiians (Braun et al., 2004; Mokuau & Tauillilli, 2011).

Most elders have close relationships with their family members, and many families provide care to keep their elder family members healthy and well. National studies have found that about three-quarters of frail older people receiving assistance rely exclusively on unpaid caregivers, who are usually family members. Personal care can include such activities as bathing, dressing, getting in and out of bed, shopping, helping to clean homes, helping with financial matters, and other tasks. Nonetheless, providing this kind of help can be overwhelming for the ‘ohana, who are often balancing jobs, childcare, and other responsibilities with eldercare. With the aging of the population, the challenges in providing eldercare will only intensify and grow. The consequences of lack of proper support for elders have been found to have significant consequences for their health and overall well-being that can result in increasing demands for health care and other interventions. Health and social services aim to help families with their care giving responsibilities. It remains critical to be able to identify beyond anecdotal tales the real issues and needs of ‘ohana caregivers and how services should be designed and delivered in a culturally acceptable and effective ways. This is especially critical for Hawai‘i, as residents of the state have a longer life expectancy than those across the nation—79.8 years vs. 76.9 years (Yuan, Karel, & Yuen, 2007).

Study Rationale and Design

Hā Kūpuna convened six roundtable listening sessions to learn more about the needs of elders and their ‘ohana caregivers. Our study participants were familiar with services offered through the State of Hawai‘i Executive Office on Aging, ALU LIKE, Inc., the Native Hawaiian Health Care Systems on the Island of Hawai‘i (Hui Mālama Ola Nā ‘Oiwī) and Moloka‘i (Na Pu‘uwai), and the County offices on Aging—the Hawai‘i Office on Aging, the Kaua‘i Agency of Elderly Affairs, and the Moloka‘i (satellite) Office of the Maui County Office of Aging.

Caregivers provide the bulk of care to elders in homes and communities. Without such care, the well-being of nā kūpuna can be severely hampered. Research suggests that there is a need to understand, identify, and meet the needs of caregivers so that they can continue to provide needed care. Unfortunately, limited data exist that describe the needs of caregivers in Hawai‘i. A recent study of care giving needs among state employees conducted by the State Executive Office on Aging has added to our knowledge base, but still acknowledges the lack of critical data for program planning purposes and questionable effectiveness in responding to needs in culturally and otherwise appropriate ways (Lum, 2008).

This study was guided by community based participatory approaches (CBPA) and principles as rooted in cultural competence with Native Hawaiian communities. The CBPA allows researchers to gain knowledge and cultural awareness of community health concerns through community-appropriate research instruments and data collection methods. Questions about health, illnesses, care, and quality of life have been found to be culturally defined and mediated, and focus group methods can help to tease out the unique cultural beliefs, values, and motivations affecting one’s health beliefs, behaviors, and overall quality of life.

Selection of Sample/Participants

We worked closely with our partners to recruit study participants who were Native Hawaiian (self defined), 60 years of age and older, cognitively alert, and willing/able to participate in a 1.5 hour meeting. Staff of the respective agencies conducted the screening of cognitive health. An 'ohana caregiver was defined as a Native Hawaiian family member who provided unpaid care to a frail elder family member, either currently or in the past year. If determined to be eligible for this study, participants were invited to participate with an introductory letter. The purpose and logistics of the study were explained, and participants were informed they would receive a gift certificate for their time. Focus groups were held on the islands of Moloka'i, Hawai'i, Kaua'i, and O'ahu.

Research Questions

Prior to the focus group discussions, interviews were conducted with key informants who were respected leaders in the Native Hawaiian health care systems providing services to families and older adults (Browne, Mokuau, and Braun, 2008). The information gained through these key informant interviews, together with a comprehensive literature review and discussions with staff from our partner agencies, guided the development of the focus group questions. (See appendices for elder and caregiver questions.) The questions were pilot-tested with two groups of multiethnic caregivers on the island of O'ahu. Comments resulted in minor changes in language choice. For example, a question on family/intergenerational support was subsequently broken down into a three-part question that asked about the provision of emotional support, in-kind (non-monetary) support, and financial support. This change was supported by other research in family/intergenerational support (Angel, 2005).

Data Collection

Data were collected through 90-minute semi-structured listening meetings that used focus group methodology. The research was approved by the Institutional Review Boards (IRB) of the University of Hawai'i at Mānoa and of Papa Ola Lōkahi and the Native Hawaiian Health Care Systems. All participants signed consent forms. At the beginning of each group, participants were asked to complete a brief questionnaire on demographic information. Due to the exploratory nature of this study, focus group format was used to yield the richest understanding of the long-term care needs and preferences of Native Hawaiian older adults and family caregivers. We chose the semi-structured interview format because it provides some structure, while also allowing the researchers some freedom to probe beyond the responses to the prepared questions, and also maximized participant comfort. One researcher led the discussion groups, while another researcher typed the participant responses on a computer, using an LCD projector to display responses to participants. This helped to assure reliability of data, as participants could comment/correct what they saw on the screen.

Analysis

Transcripts were analyzed for themes using the constant comparison method developed by Strauss and Corbin (1990). This method allows researchers to “group answers...to common questions and analyze different perspectives on central issues” (Patton, 1990). Members of the research team independently annotated and highlighted key findings, categories, and potential quotes. We used the

method of constant comparative analysis. Coding was continuous, followed by the comparison of coding systems, discussion and consensus agreement. The categorization of each response was not finalized until two coders reached consensus. Quotes were identified to illustrate the range of opinions and comments to support the identified themes (Curry, Nembhard, & Bradley, 2009).

Study Results

Sample Description

A total of 24 kūpuna and 24 ‘ohana caregivers participated in this study. Among participating kūpuna, only five received care from those who attended the caregiver meetings.

The kūpuna participants consisted of 24 participants (21 female and 3 male) residing on the islands of Moloka‘i, Hawai‘i, Kaua‘i, and O‘ahu. Their ages ranged from 60 to 94 years, with a mean age of 77. All claimed Native Hawaiian ancestry. We asked participants their percentage of Hawaiian ancestry, and the responses ranged from 20% to 100%. It was a moderately educated group, with 15 having some high school or GED and eight with some college. Only one kupuna identified needing help on a regular basis (about eight hours per week) for the past three years. The remaining kūpuna did not require any assistance on a regular basis. Demographic and background questions asked the participants to identify their most common areas of assistance. The types of support that was provided on occasion were cooking, cleaning, shopping, paying bills, and, going to the doctor. Responses listed less often included bathing, dressing, eating, or getting in and out of bed. In answer to our question, “who provides the assistance,” most said adult children and/or spouse. One participant used a paid caregiver for assistance. However, in response to the question: “who helps you the most,” the most common response was spouse.

The caregiver group consisted of 24 participants (19 female and 5 male) who resided on the islands of Moloka‘i, Hawai‘i, Kaua‘i, and O‘ahu, All were providing care or had been providing care to an older family member. Their ages ranged from 38 to 77 years with a mean of 57 years. We asked participants their percentage of Hawaiian ancestry, and the responses ranged from 10% to 87.5%. One individual responded that she was not Hawaiian but was married to a Hawaiian and “felt” Hawaiian. In terms of employment, about one-half of the caregiver groups (n=12) were presently working outside of the home. Twelve had some high school, and another twelve had some college. The kūpuna care recipient was a parent, followed by a spouse, sibling, and uncle. The number of hours spent per week providing care ranged from two hours per day to 24 hours per day. The most common areas for providing assistance were with shopping, going to the doctor, cooking cleaning, bathing, medications, and paying bills. The average years of providing caregiving was seven years (range from 3 to 10 years).

We provide data from both the kūpuna and the caregiver groups. Comments from participants are illustrative of both common themes and the range of comments.

Section 1: The Concept of Kūpuna. We asked the question: How do you define a kupuna?

Elders and caregivers spoke positively about the concept of kūpuna in their own families and in the Hawaiian culture. Common descriptive terms spoke of the wisdom that comes with age (“*a kupuna is knowledge*,” *a kupuna is “...when someone has experience in life”*) and the sharing of this knowledge (“*a kupuna is one who teaches*”). A number of participants associated kūpuna with issues of cultural preservation. For instance:

A kupuna is one...who knows the arts.

A kupuna looks to the past and future. Kūpuna are the ones with the knowledge—wisdom. They respect Hawaiian values and deserve respect.

While some attributed the term kūpuna to physical attributes (“white hair”), there were interesting variations. A number commented that they did not think the word kupuna referred to a Hawaiian elder, but to any older person. And, while some commented the term was related to age (“more and more, your 70s and 80s you are getting old—you are kūpuna”), many more did not agree with this interpretation according to number of participants:

... no age, depends on who you [are] as a person; how you provided services; a respected ‘giver’, [someone who] did things for people, helped others...

People say by age but I don’t think so. You can be young and be a kupuna. I think age is a western concept because you can get benefits when you reach a certain age. You can be young and be a kupuna. It’s not the Hawaiian way [to equate age with kūpuna]—it’s a western way.

Participants in every group suggested that kūpuna was a term closely connected to grandparenthood. Kūpuna shared that they provided care to their mo’opuna (grandchildren), and this made them grandparents and kūpuna. For instance:

When I think of kūpuna, I think of grandparents—I think of love. They have so much patience and love.

I was young but I had grandchildren. So that made me a kupuna.

Kūpuna comes in any age. Even if you are 50, you feel like kūpuna when they pile up the kids on you. It comes with your job. The children bring their children [to you] to care. Now I am kupuna.

Another topic that emerged in each group was the kūpuna’s belief in kuleana to his or her family and for cultural preservation. One kupuna said:

... I feel responsible for both the older and younger generations—it is the Hawaiian way.

And another comment:

Kūpuna ...pass down culture, religion, values, in the right way to the next generation.



“A kupuna looks to the past and future. Kūpuna are the ones with the knowledge—wisdom. They respect Hawaiian values and deserve respect.”

Section 2: Keeping Kūpuna Healthy. We asked: What do you think are the health needs of Native Hawaiian elders? How can we keep kūpuna healthy?

This question elicited a range of responses, but the most common suggestions to keep kūpuna healthy included the importance of: 1) healthy diet; 2) adequate income; 3) respect [from service providers and from their families]; and 4) ease of accessibility to specific health and support services. Comments reflected the cosmographic view of health among Hawaiians that health has physical, emotional, and spiritual components (Mokuau, 2011).

Subtheme #1: Healthy Diet. Participants agreed that Hawaiians need to eat healthy. There were many references to the importance of taro and poi in the Native Hawaiian diet for both physical and emotional health (“taro—it’s part of medicine,” and these statements: “We eat lot of poi and that’s very healthy. If you want our mana’o, that’s where it is” and “Poi—it’s our bread and butter”). Poi was also viewed as spiritual, in, “It’s not just food—it is the spiritual connection to poi—the source”. Some related poor diet to the effects of colonization as in:

Native Hawaiians had the healthiest diet until western influence. [We] need to control what is eaten today, and go back to the eating healthy [ways].

Others noted the desire to eat healthy, but the high costs of doing so. One participant stated:

Everything to keep costs down. Fish and poi healthy but expensive. Use to grow them.

Subtheme #2: Adequate Income. All groups discussed kūpuna’s need for adequate income. Numerous participants commented about finances and the challenges of both growing old and providing care with limited resources and high health care expenses. Comments ranged from the expenses related to kūpuna’s unexpected hospitalizations to the fact that adult children are less available to care for their aging parents due to competing work and family responsibilities. For instance:

My mom doesn’t qualify for anything, yet she can’t afford to pay for the services she needs—even though she doesn’t qualify. Lots of middle class kūpuna falling through the cracks because don’t qualify but can’t afford—that needs to change; can’t get respite, other services. I quit school to care for mom but I worry when she becomes bedridden—how will I pay to get her nursing. Been saving but now I don’t qualify for grants.

...comes down to income, lost without it, depend on that money; when hospitalized and takes that money, takes your whole life away... nothing to live for, if they [kūpuna] could stay home instead of hospitalized. Hawaiians are proud, once you take things away pride is hurt.



“Native Hawaiians had the healthiest diet until western influence. [We] need to control what is eaten today, and go back to the eating healthy [ways].”

We need help learning about finances. That's difficult—we need to learn about financial aid.

Handicap accessibility—no money to fix house; even when apply for help—list is so long that it takes forever.

And this often heard comment:
Why is everything so expensive?

Subtheme #3: Respect for Kūpuna. Many comments described the importance of providing respect to kūpuna, whether it was from the family or service providers. Some of the comments from kūpuna:

Family responsibility for caregiving—it is not a professional designation.

As Hawaiians, we brought up to care for one another. Living in [the] states, you old, we put you in a home. Not in Hawai'i. Families talking about putting aunty in home, but here I take care of mom. We are taught that as children.

For other kūpuna and caregivers, issues around respect centered on the elder's desire for independence and reluctance to ask for help (*"kūpuna demoralized—cannot do but want to do"*). Other commented:

You hit an age, we want them to be independent, but force them to be dependent, because things that would allow them to be independent are not available; loss of pride, worth, no choice.

Kūpuna would like to enjoy life, but their family comes first. They take home to care for mo'opuna while children work. Can't enjoy life. Can't come to Center because have to babysit.

I feel guilty asking my kids to help.

And this comment by a male caregiver:
It's hard for males to take care of their mothers.

Participants in all groups also voiced some anger around what they observed and had experienced with agency and hospital staff that were insensitive and disrespectful to kūpuna (lack of humility, or ha'aha'a). This often led to kūpuna not returning for needed services. For instance, this comment spoke to a preference for a culturally informed provider:

Staff need to be trained to work with kūpuna. Kūpuna may not answer right away staff walk away, kūpuna need respect.

Communication is easier [with a Hawaiian provider].



"We need help learning about finances. That's difficult—we need to learn about financial aid."

Hawaiian doctors coming home, maybe they can work here. Funding has a lot to do with it, some programs come and go.

Subtheme #3 Ease of Accessibility to Specific Services. Other comments discussed specific services that could help the kūpuna stay healthy. These included having choices for services and activities (“*not all kūpuna are alike*”) and transportation (“*kūpuna get isolated and sad*”).

Not all want program and services. Took mom to adult day care—but mom didn’t like it because “it’s for dummies”—so mom refused to go back. It has to be the right fit [for the person].

Everyone has different kind of personality. People who know the kūpuna well should find the best fit programs and that would be their needs, individual needs not dependent on their ethnicity or culture.

Transportation was mentioned by many as a potential solution to combating isolation and loneliness and to help relieve family of transporting the elder to doctors’ appointments.

Also, many at home have so much vitality—can offer so much to the community. For me, ALU LIKE is the only one who provides that on a daily basis.

To me, the greatest need is getting our kūpunas out. Getting transportation.

Section 3: Keeping the ‘Ohana Healthy. To draw out participant thoughts about ways to keep ‘ohana healthy as they provide care to their kūpuna, we asked: What does the ‘ohana need to provide care and stay healthy? We also asked if the ‘ohana had specific needs that impact their abilities or influence their willingness to provide care to their elder (e.g., identification of health and long term care needs).

This question elicited the most engaged responses in every group. Some ‘ohana needs were seen as the same with all caregivers, native or non-native (“*we all grow old,*” “*aging is universal,*” and “*caregiving is hard*”). Kūpuna and caregivers acknowledged the commitment and time in caring for kūpuna, yet, they had mixed feelings about using formal services.

Caregivers discussed their own health challenges, i.e., arthritis, diabetes, and heart disease. A number of participants shared the importance of their spirituality to sustain themselves in difficult times. (“*Spiritual support? It is the only way,*” and “*I pray, I read the Bible.*”)

We asked if the needs of Native Hawaiian elders differed from needs of elders of other ethnic and cultural backgrounds, and if Native Hawaiian elders should only be cared for by other Native Hawaiians? This question elicited mixed responses. Although participants viewed the challenges of aging as a universal phenomenon, differences regarding diet and ‘ohana were identified. Responses regarding their views on health and social service staff who worked with elders were mixed. Some participants commented that the ethnicity of personal assistants was irrelevant, as long as the person had the skills appropriate to provide the care. In contrast, one respondent did not answer the question directly but suggested that Hawaiian families “*...take care of their elderly parents...that was the better way.*”

My husband’s family is Hawaiian and I do believe that they are more predisposed to taking care of the ‘ohana—it’s important to them.

Primary subthemes derived from this question included: 1) financial needs and burdens related to care giving; and 2) needed supports and services (education) for ‘ohana caregivers. One caregiver said:

My wife—[I’m] helping her. [She has an] Incurable disease. [It was] Hard at first, especially [the] first 23 years. I have come to learn—and settle down. I worked in an area where things had to be done at a certain time, but with this, it boils down to love, respect, caring. It’s hard at first, expensive, [and] you have to tone yourself down. There is anger management, too. And [with] medications, [she] needs help with meds, shopping, driving. Other things, she can do—wants to do. She is 77 years old. I found out [that] a little more caring is good. [It’s] Hard, very hard work. I am not kupuna, or caregiver, I am just a responsible—a responsible husband.

Subtheme #1: Financial Needs and Burden. Embedded in care giving are numerous financial, service, housing and health care costs. A number of families discussed the additional challenges related to balancing work and care giving. (“You can help take care of someone, but no one will help you financially,” and this comment: “Day care is good but expensive.”)

Some participants talked about barriers to getting financial assistance.

I am lucky [I] finally got on the program [chore services]. Because I live with my mom and have a full time job. I take off work sometimes to care, and I lose money then. [There is] No choice, my main purpose is Mom. I signed up for chore [services], 1.5 years later, [I] got it. [It] Helps, but [a] faster process would help... [the] long wait. Lots of sacrifice... job wise, it hurt me. But fortunately, my managers are understanding. [It’s hard] Being burnt out [with] no extra help.

Subtheme #2: Lack of ‘ohana support services and education. The second theme—the absence of support for family caregivers—emerged in response to questioning about the ways to keep the ‘ohana healthy. The most often cited response was the need for family caregiver education and support services. (“We need since we are doing the caregiving.”)

I wish they had programs for us, like, classes; like, in health and nutrition. At [my] Aunt’s house [program staff] came in and helped us [learn to] break some of our bad habits. It’s some place for me to go instead of staying home all day. Taught me to go shopping and pick healthier foods; but they stopped that.

One respondent felt that issues around the need for independence could be met with more staff training (“Patience—staff need patience,” and this one: “I had a haole doctor. But now I feel comfortable because I have [a] female doctor. It was more gender but maybe [to] a certain degree with Native Hawaiians”).

Others discussed the emotional challenges of caregiving and the importance of learning more about understanding the aging processes and strategies to deal with difficult and demanding situations.



“I signed up for chore [services], 1.5 years later, [I] got it. [It] Helps, but [a] faster process would help... [the] long wait.”

My wife [was] diagnosed with breast cancer. She wanted to keep working; [her] company let her leave [for] chemotherapy, radiation, and drip. It was hard, 44 years-married, and this happened 5 years ago. My girls have their own families. I need[ed] to make sure she takes her shot; I just got out of the hospital, [for] surgery on [my] foot... for two weeks. The point being, I could still get around, little more slow[ly]. We made commitments to our spouse, [and] you do it.

I take care of Mother. [She's] Alert at times, [she] chooses to forget things (group laughter). I have seen her health go down. [I was] Living on mainland, [and] came back 6 years ago. She took care of me, now, I take care of her. Being [at] home I have learned a lot, health care medical care, what is wrong insurance, medications, daily routine, she is active in ALU LIKE, but her [ill] health has taken a toll. [I am] Trying to learn what she needs, at first keeping up with changes. [When] you get his [doctor's] automated line, [it's] frustrating!

Section 4: Worries and Concerns. We also asked: Many people think that caring for an elder is a family responsibility; others think it is a responsibility of government. What is your opinion on this?

The majority of respondents believe that caring for an elder is a joint family and government responsibility. They talked of the need for some kind of cooperation between the government and the family that could help the family before the family exhausted its resources. Not all agreed. One participant had this to say:

Why should it be the government? There is only so much dollars you can get from the government. As a people, we should take some responsibility too. Hawaiians are akamai (wise) because we have a system of hanai (adoption). Sometimes government and health are ridiculous—create their own paperwork.

Finances were a consistent and major concern in each listening group. Specific to this question, two themes emerged during this discussion: 1) care giving as a responsibility of both the family (a family kuleana) and the government; and 2) rules, policies, and procedures that provide barriers to financial and kūpuna independence. Three of the respondents felt that the government has to have a role in taking care of their elders and their families: (“Why can’t government pay families to provide care? They pay strangers”). Another respondent suggested that the government should pay for the medicines.

Medical insurance so confusing, especially Part D. What does it cover? So much things to worry about. She (wife) has a thick book for Medicare. If this place (on the Big Island) is a clearinghouse, necessary and good. Insurance—important—have to understand but a challenge. I am wrestling with all of this information.

I think something like a conference would help us caregivers and without daily responsibilities and issues. What kinds of program to use...



‘Medical insurance so confusing, especially Part D. What does it cover? So much things to worry about. Insurance—important—have to understand, but a challenge. I am wrestling with all

We attempted to draw out more specific comments about intergenerational supports to further uncover the financial and other resources provided to elders from their families. Unmet needs often help to identify gaps in care services. The question was asked in this way: Think about a close friend who is Native Hawaiian, 65 years, or older, who has adult children still living. Does this kupuna receive any emotional support, in-kind support, or financial support from his or her family? There was a generally positive consensus that kūpuna do receive emotional and in-kind support from their families, although not financial support. Examples of in-kind support can be housing, transportation, and help with medication. One respondent mentioned that sometimes, even if there are multiple children in the family, the brunt of the work often falls to only one child, while others (children) are effectively absent. Another participant shared that, sometimes, the family doesn't want to help. In such a situation, the kupuna may turn to his or her friends for support. The response to whether or not kūpuna receive financial help from their family elicited a mostly negative response. One respondent shared that sometimes it is actually the adult child who depends on the kupuna for financial support, not the other way around. Other respondents shared that kūpuna give care, not just receive it, as in caring for their grandchildren.

Discussions identified reasons why families did not use services even when eligible, available, or accessible. Primarily, other family members do provide care—it is the family kuleana (responsibility). Competing demands on caregivers occur primarily with finances and balancing of work and family responsibilities. Two common issues mentioned were: first, kūpuna and their families may not know about services; and secondly, kūpuna may be reluctant to ask for help. Some participants felt the latter comment was culturally-based, as well as an issue of pride (i.e., not wanting to ask for help).

As one elder said:

You expect your family to know—you should not have to ask. Service providers may ask once, and if get “no” they go on to next question. [It's a] Lost opportunity.

Returning to the question of who should be responsible for kūpuna care (‘ohana or government), some felt that receiving government care goes against the family's kuleana to care for its elders. However, greater numbers of participants noted that some caregivers had their own matters to attend to while caring for kūpuna—employment and other family responsibilities—resulting in the need for government support. Lastly, geographic location was viewed as a determining factor in not providing or using services. Sometimes kūpuna and their families live too far apart to provide constant assistance. The majority of all participants resided in rural areas where service accessibility is mostly problematic. The majority of the respondents turn to their friends and families for help, which shows the importance of extended-family networks and non-kin relationships.

Section 5: Barriers to Health and Care. Have you had any positive or negative experiences with care giving for an elder that you would like to share?

Respondents identified a number of barriers to health and health care, and wanted the barriers removed. Rules and regulations that make accessibility and use difficult were discussed. Some participants wondered why ‘ohana caregivers could not be paid to provide family caregiving. (“*They [health insurers] pay strangers—why not families?*”)

Along with family education and support, and transportation, available and affordable respite services were among the preferred services. There were many comments about respite care (“...when my husband was sick, you need to get out to cope...”); family education and support (“we need education—we are not doctors”); and transportation (“hard to get to services without car”). A number expressed appreciation for services from the Native Hawaiian Health Care System and ALU LIKE, Inc. on their respective islands. Among participants who had used other federal, state, and private help, a number commented that they were disappointed and stopped using the services due to intrusive admission/eligibility procedures, disrespectful and rude staff, and inflexible rules and regulations.

A major barrier to service are the income eligibility rules perceived as unfair. Participants noted that family income is counted for service eligibility, often leaving the elder ineligible. A number of participating kūpuna and caregivers made references to a “gap group,” or people who are not poor enough to qualify for government assistance, but are not wealthy enough to make it on their own. Those in the second group are technically overqualified for governmental assistance. Four respondents discussed a particular issue for Native Hawaiian elders that centered on kūpuna whose names appear on old family land titles. While these kūpuna do not receive any revenue from such lands, they are disqualified for assistance because the lands are counted as “liquid assets”.

Many elderly people don't even know but their families own land so they don't qualify for financial benefits. Welfare, food stamps. [They are] Forced to sell that piece. Not even able to remove their name from the property. [There are] Lots of homeless Hawaiians because of that.

Other comments described unhappiness with agency practices and regulations:

You go to the food bank, and they ask you how many in your family... but it doesn't matter, the number of family. So where are we Native Hawaiians? We are on the bottom. It's not being distributed to Native Hawaiians.

I was denied service when the income of my adult son, as well as my husband's retirement payments, were considered in my application.

Requirements say, only spend one hour with client. Limited by the rules, hard to explain. Administrators need to hear from clients.

[Good care is when] They don't make you feel like dirt. [So many] ...questions [that are asked] don't pertain.

They want to know everything about you. I was only \$2.00 over [eligibility] and got nothing. Tried to get SS [for husband, but they] said he wasn't handicapped enough. [Although] He was in a wheelchair, and he had medications. So never mind



“[Good care is when] They don't make you feel like dirt. [So many] ...questions [that are asked] don't pertain.”

already—I don't need help.

Caregivers shared comments around why kūpuna may not use services that are available, and potential reasons behind this reluctance. Comments here focused on the reasons why elders may be reluctant to use services. Participants speculated that kūpuna and caregivers don't know how to ask for help, don't know about services, and have a need for privacy. Moreover, the administration of the program/service may be such that kūpuna and caregivers don't want to use the services (*“lack of staff compassion, don't make you feel you are so poor, you need me”*).

For instance:

Our people do not want to expose private details and are reluctant to tell problems [to strangers]. Caregivers frustrated feel like “why you not disclosing?” Because we feel shame. Need to meet the need without making them feel like they are a burden. Need to project compassion so don't lose dignity.

People in cities use services, but people in country, old Hawaiians won't. Turned away many times so won't use.

Additional comments included:

[In the] Plantation era, [we] worked hard. Too much pride to ask [for help]. I can take care of myself. [Agencies ask] Too much questions. I don't want to answer. I just want help. It's private.

Turned away, just out of disrespect. [They are] So rude, no respect. [Just] Because she's poor, handicapped. Nobody deserves to be treated like that.

Additional barriers to care included the high cost of health care and health insurance. Four participants spoke on the high cost of health insurance, particularly the cost of prescription medications, an issue that affects Hawaiians and non-Hawaiians alike. A few participants stated that, because Hawaiians are less affluent, their children are less likely to be able to take care of their parents financially. Again, as most of the listening meetings took place in rural neighborhoods, participants expressed the need for more services in their own communities, so they did not have to travel or relocate to more urban areas.

Respondents commented on the need for more family education classes. A number discussed the need for Hawaiian practices.

Teach us to cook Hawaiian food. My Dad used to cook. This is our culture. Teach us net making.

Additional barriers to care focused on housing—the expense of housing and the lack of availability of affordable housing. (*“Housing is a crisis. Always filled—everybody needs more kūpuna housing.”*)

Section 6: Facilitators and Services. What programs or services do you prefer and use? Why did you use this program or service?

Although kūpuna and caregivers shared their negative experiences with inflexible rules and regulations and uncaring staff, they also had positive experiences to share. They expressed

appreciation for the services of the Native Hawaiian Health Care System on her island and the services of ALU LIKE. A conference on aging was thought to be very helpful by one caregiver:

This conference [on aging] really helped me, taught me things. Medicare is not enough. Education is needed, sometime they angry. My dad has Alzheimer's Disease, died at 88 years, he died of cancer. Sad thing about AD, he could not speak, could not recognize. How do you tell your caregiver you are in pain? He would get angry. This type of information is needed, not just for caregivers but the general population. Don't wait until the need for caregiving starts.

Participants talked about the need for cohesion and consistency in the system of elderly care. While Hawaiian culture emphasizes care of kūpuna (“...as Hawaiians, when you grow up, you take care of kūpuna”), the financial demands of care giving can be daunting. Elders and families noted that access to services was confusing and difficult to understand. What did work was to become familiar with a community service through a neighbor or friend. It also helped that, once connected, they became familiar with a staff member who they learned to trust and feel a level of comfort. Other helpful tools identified to improve care were agency personnel who were culturally informed, professional staff who made home visits, services that were affordable, and organizations whose policies and procedures were respectful and not intrusive (i.e., privacy issues). Helpers often were referred to as nurses or social workers.

Section 7: Suggestions. In our last question, we asked: Is there anything else you would like to share on this subject?

Seven respondents, with agreement from many others in each group, spoke about the need for respite care and time for oneself as a caregiver. Three respondents spoke on how helpful it is for siblings and other family members to take turns in caring for the elderly parent, but that not all do. It was unclear if this comment spoke to the need for respite care or a preference for family support instead of hiring a respite worker or volunteer. Both kūpuna and caregivers used words that spoke of the values of pride and independence as they relate to accepting help from others. For the kūpuna, this concern is related to the fear of becoming a burden to one's family and to others. One participant said this:

[Hawaiians] Proud people. Grew up with an inferiority complex, some haven't been able to climb out of the puka.

There were also suggestions on how to inform kūpuna and caregivers of services in their community:

Information has to get out to community about what's available kūpuna don't want to say how they feel. They shut down—it's private. Don't want to make waves.



“Information has to get out to community about what's available. Kūpuna don't want to say how they feel. They shut down—it's private. Don't want to make waves.”

A number of participants suggested that the Office of Hawaiian Affairs should have a program for kūpuna.

OHA needs to create “office of the kūpuna” for all that kūpuna need—shouldn’t have to be running all over the place to get the help you need...

A few wondered why such an office did not exist (*“surprised that nothing like that is in place already”*) and were surprised that OHA did fund a number of aging-related programs. Another commented:

...want something in place to protect caregiver because there is no protection—I was falsely accused even though doing something to help mom; it’s my duty (to care) but caregivers need help too.

Finally, a list of other suggestions included:

- A life course perspective to aging. (*“Have to start at younger ages [to be healthy]. In this center, a nutritionist helps. That we can access. This would be a good thing to fund.”*)
- More health promotion and prevention programs. (*“More and more elderly women with breast cancer. More prevention and screening. Some never had mammograms.”*)
- More nutrition programs. (*“We should have the lunch site program they have on Maui.”*)

Discussion

Drawing from the data, we can summarize five major themes that emerged from these kūpuna and ‘ohana listening discussions on health, long-term care and well-being needs, concerns, and preferences. For the most part, both kūpuna and caregivers held similar concerns. These include: 1) financial worries and concerns; 2) health and care giving concerns; 3) barriers to well-being; 4) role of kūpuna in eldercare, culture, and cultural preservation; and 5) preferred services.

Financial Worries and Concerns

The financial challenges of growing old and for providing care giving were discussed in every group. The high cost of food, health care, and support services were topics of major discussion. We asked if families provided financial support to elders, and the answer was primarily a “no”. Families found it difficult to provide financial assistance due to the competing demands of family and work. The nation’s long-term care policies contribute to this inconsistency. Sources of funding for long-term care are, most often, Medicare and Medicaid. Medicare focuses on acute care, rather than long-term care, and only covers the long-term care costs for skilled nursing care or rehabilitative treatments (Lehning & Austin, 2010). Medicaid is a “means-tested” program that funds for long-term care. Older adults who receive support from their families may not be eligible for Medicaid. Native Hawaiian kūpuna face additional eligibility challenges. Family financial status is a major barrier to providing monetary support. And, elders who fall in the lower socio-economic group may find institutional long-term care inaccessible, because community residential care is cost-prohibitive.

‘Ohana who do want to help frequently have their own health concerns and often become isolated while providing care to elders who become increasingly more dependent. Families want access to respite care for home-bound elderly, however, financing these support services is beyond their personal financial capabilities and there are no outside funding resource. Elders and their caregivers hoped to “age in place”, but realize that to do so, they needed financial and service supports from family members and government providers.

Health and Care giving Concerns

Nā kūpuna (elders) and their caregivers discussed the need for constant adjustment in the caregiver role to accommodate the fluidity of changes in aging. All groups readily discussed increasing care giving expectations of families to meet the needs of elders with advanced age. Kūpuna hoped to age-in-place, but similar to their ‘ohana, they had little knowledge of the greater health risks among Native Hawaiians compared to their counterparts of other ethnicities in Hawai‘i. This has implications for health promotion, prevention, education, and treatment services from the Native Hawaiian Health Care System (NHHCS), ALU LIKE, Inc., and other health care providers. The NHHCS and ALU LIKE were specifically mentioned as Hawaiian agencies that helped elders remain at home. The concerns of nā kūpuna centered on maintaining a healthy diet, an adequate income, respect from family members and service providers, as well as, accessibility for specific support services. Family concerns focused on the financial burden of care giving, barriers to accessing services, possible reluctance of nā kūpuna to ask for help, and their limited healthcare education, as well as support

services. Families sought help with learning to perform the required medical tasks, yet, were troubled by non-responsiveness of organizations (see the following comment). On the Island of Hawai'i, the Hawai'i County Office of Aging's "one-stop-shop", was recognized for the way it increase access to information and services.

Kūpuna and their caregivers identified many challenges to "aging in place" — service access, quality of professional and culturally-informed providers, and the need for specific services, such as: respite care, transportation, and family healthcare education and support. Families want to provide care, but need financial and service support from family and government sources.

In addition to the services identified above, the need for affordable senior-housing was discussed as a means of encouraging autonomy and independence. Other caregivers voice the importance of kūpuna activities to forestall institutionalization. Elders and caregivers did not want more access to nursing homes, rather, they desire improved services to allow elders to remain at home for as long as possible. 'Ohana identified three care-services: respite, transportation, and family education, as most important in helping to keep elders at home.

Barriers to Well-Being

A number of federal, state, and private organizations provide support services to the elderly that promote independence and provide family care giving support and that potentially delays institutionalization. Most elders (and caregivers) were open to receiving services and welcomed them because they are helpful to kūpuna. However, these services are often unaffordable to individuals with financial limitations. Financial limitations also present barriers to healthy eating and living in safe neighborhoods, as well. Some participant comments focused on frustration with agencies and organizations that make accessibility difficult, through eligibility rules and regulations, intrusive admission procedures, and insensitive staff who were not trained to work with nā kūpuna (i.e., disrespectful).

Frustration was expressed by both kupuna and caregiver over an issue related to land ownership that affects Native Hawaiians. Kūpuna are often unaware that they are named on old-family land deeds that disqualify them from services (e.g., Medicaid/Quest). This happens even when the kūpuna do not have any benefit from the land. Kūpuna are also reluctant to seek services because they have experienced the intrusive procedures and insensitive, disrespectful staff who are not trained to work with kūpuna.

Poor service delivery in long-term care is an issue due primarily to inadequately trained and supervised professional and paraprofessional (direct care) workers, i.e., nurses' aides, companions, home care assistants and social work assistants (Lehning & Austin, 2010). Home and Community Based Services (HCBS) cite difficulty finding qualified, committed individuals to provide services and care, and a high turnover rates among paraprofessional employees as causes for service problems. Low wages, poor benefits, heavy workloads, difficult working conditions and a lack of qualified applicants are also contributing factors. Another important factor in Hawai'i, is the lack of knowledge about the Hawaiian culture, as well as "local" values and customs, and the importance of ha'aha'a (humility) when working with elders. One participant told of how his mother's new worker entered the house wearing her shoes and called his mother by her first name, and this was viewed as disrespectful. His mother refused to allow the worker return.

Role of Kūpuna in Eldercare, Hawaiian Culture, and Cultural Preservation

Cultural issues were woven into the fabric of every listening meeting. Although participants acknowledged that aging was generally universal, there were many comments related to eldercare in terms of culture and cultural preservation. Points discussed were: the kuleana (responsibility) of family to provide care for kūpuna; the elders' concerns about being a burden to the family; the importance of prayer and spirituality in supporting nā kūpuna and caregivers; the Hawaiian cultural role of kūpuna in the 'ohana and in preserving culture, as well as, the importance of sensitivity to privacy and respect in elder and 'ohana communication. Cultural issues were expressed about how listening meetings were conducted, for example, the cultural preference for beginning meetings with pule wehe (opening prayer). These points have implications in healthcare worker training, as well as designing, delivery, and accessing health services, and for future research.

What participants did not comment on were the health risks and shorter longevity of Native Hawaiians. Those health practices, conditions, and diseases that are more prevalent among Native Hawaiians include certain types of cancer, diabetes, asthma and obesity, and health practices such as smoking and drinking (Braun et al., 2010). We are not sure if participants did not want to share this information with us, did not know that Native Hawaiian longevity is the shortest among the five major ethnic groups in Hawai'i, or that a lack of knowledge around the consequences of harmful health practices (i.e., diet) can contribute to poor health.

Preferred Services

Elders and caregivers identified several services that they would like to have increased and more available. These included caregiver education and support services, respite care, and transportation. The elders and caregivers identified the need for increased staff education to assure sensitivity to Native Hawaiians, aging issues, and care giving concerns. They wanted more professional education and training, as universities may now offer coursework in aging, but many professionals and paraprofessionals in the field remain untrained. This is particularly true with respect to cultural competence and aging. Organizations that provide services to older adults and families need to be informed of standards for cultural and linguistic competency in health services and adhere to these standards. Health organizations need to commit to educating their staff and insist on respectful care for all elders. Culturally-informed practices and policies promote responsive care that can impact eligibility, access, and service utilization. Organizations such as Hawai'i's Executive Office on Aging and the Native Hawaiian Health Care Systems need to review their services to determine if kūpuna and 'ohana needs are being met.

Summary and Recommendations

A total of 48 elders and caregivers participated in these listening discussions on the islands of Molokaʻi, Hawaiʻi, Kauaʻi, and Oʻahu. Overall, nā kūpuna hope to age in place with respect, and ʻohana caregivers hope to continue to care with help with affordable, accessible, and culturally informed support services and education. The most preferred service for caregivers was respite care, so the caregivers can take care of themselves while caring for their kūpuna. Participants also wanted: 1) more comprehensive and affordable programs that encompass the many needs of nā kūpuna and their caregivers, e.g., respite, transportation, caregiver education and support; 2) more affordable and accessible health plans for nā kūpuna that include home and community based long-term care services; 3) attention to and removal of barriers to service eligibility; and 4) affordable and efficient services and programs designed and delivered by culturally informed personnel.

Study Limitations

This study should be replicated so that study primary limitations—small sample size and limited generalizability—can be addressed. More research should be conducted regarding the long-term care needs and preferences of Native Hawaiian elders and their families with a more robust sample size to ensure reliability and generalizability. This will allow study findings to have a greater impact on policymakers and professionals who are dealing with the burgeoning aging population. Our kūpuna and caregiver inclusionary criteria (that they be physically able to attend a 1.5 hours focus group) means that our sample was relatively high functioning, which may have contributed to responses that reflect a more independent and active lifestyle. Participants in this study were recruited through the Native Hawaiian Health Care Systems, ALU LIKE, Inc., and the state and county offices on aging. This means that most members of the sample were using services. This selection method, combined with agency connection, may have influenced their answers.

Final Recommendations

Given the parameters around the limitations of this study, we can suggest the following.

Greater attention must be focused on:

- Promoting healthy aging and aging-in-place;
- Increasing kūpuna and caregiver access to financial, social, mental health, and other support services and resources;
- Increasing family access to respite care, transportation, and caregiver support and education;
- Having federal, state, and private sector organizations review policies for potential barriers to services; and
- Educating professional and paraprofessional staff to be respectful to Native Hawaiian elders and their families and to consider the key role of culture in service provision and support.

National and state demographics argue for the need to advocate for livable or aging-friendly community for **all** elders. Growing old may be a success story, but brings with it many challenges of aging that require societal and family responses. An age-friendly community is one where “older adults are actively involved, valued and supported with infrastructure and services that effectively accommodate their needs” (Lehning & Austin, 2010). Affordable community design, adequate housing options, a wide range of transportation choices, and access to health care, supportive services and opportunities for community involvement are essential components. This need has never been greater. The generally poor health profile of Native Hawaiian elders emphasizes the importance of an age and family-friendly community. In the end, communities are strengthened when all kūpuna receive the respect and care they deserve, and when policies support families in the care they want to provide.

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Appendices

Appendix A Questions for Elders

Appendix B Questions for Caregivers

APPENDIX A

University of Hawai‘i
MBT School of Social Work and
Hā Kūpuna: National Resource Center for Native Hawaiian Elders

Focus Group Questions: Elders

1. What is your name, and how do you define a kupuna or elder?
2. What do you think are the health needs of elders?
3. Are the needs of elders different or the same depending on their ethnic and cultural background?
4. What about the needs of the ‘ohana of kūpuna —are you aware of specific needs families may have in their abilities or willingness to provide care to their elder?
5. Are these needs the same or different depending on the family’s ethnic and cultural background?
6. Think about a close friend who is 65 and over, who is of the same ethnic and cultural background as you, and who has adult children still living. Does this elder receive from their children:
 - a. Financial help
 - b. Emotional help
 - c. In-kind help (e.g., housing trips to doctor, help with food, etc.)
7. What programs or services do you prefer and use? Why did you use this program or service?
8. Many people think that caring for an elder is a family responsibility; others think it is a responsibility of government. What is your opinion on this?
9. Have you had any positive or negative experiences related to services or family caregiving for an elder that you would like to talk about?
10. Is there anything else you would like to share on this subject?

APPENDIX B

University of Hawai‘i
MBT School of Social Work and
Hā Kūpuna: National Resource Center for Native Hawaiian Elders

Focus Group Questions: Caregivers of Elders

1. What is your name, and how do you define a kupuna or elder?
2. How would you describe your general health?
3. What do you think elders need to stay healthy?
4. Are the needs of elders the same or different depending on their ethnic and cultural background?
5. What about the needs of the family or non family caregivers —are you aware of specific needs these people may have in their abilities or willingness to provide care to their elder?
6. Think about a close friend and non-family member who is providing care to an elder. Does this friend provide any of the following to his/her elder family member:
 - a. Financial help
 - b. Emotional help and support
 - c. In-kind support (e.g., housing, help with getting and taking medications)
7. What are some of the reasons for this family providing or not providing assistance to this elder?
8. What community programs or services have your preferred and used? What are some of the reasons for this?
9. Should you need support or help in caring for an elderly relative, who do you turn to?
10. Many people think that caring for an elder is a family responsibility; others think it is a responsibility of government. What is your opinion on this?
11. Have you had any positive or negative experiences with caregiving for an elder that you would like to share?
12. Is there anything else you would like to share on this subject?