

**Assessing the Health and Long-term Care
Needs of Native Hawaiian Elders and Their
Caregivers: Results from Key Informant
Interviews in Hawai'i**



September 2008

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

University of Hawai'i
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Acknowledgments

“Assessing the Health and Long-term Care Needs of Native Hawaiian Elders and their Caregivers: Results from Key Informant Interviews in Hawai’i”, is a report of Hā Kūpuna, the National Resource Center for Native Hawaiian Elders. The staff of Hā Kūpuna sincerely thank the members of our Native Advisory Council for guiding us with this study. These include the Honorable Daniel K. Akaka (Honorary Chair), and Drs. Claire Hughes (Co-Chair), Kekuni Blaisdell, J. Keawe’aimoku Kaholokula, and Shawn Malia Kana’iapuni. We also extend a warm mahalo to members of our Partner Organizations Advisory Council, whose members include: Mr. John Tomoso (Chair), Ms. Kealoha Takahashi (Vice Chair), Ms. May Fujii Foo, Sister Alicia Damien Lau, Mr. Wesley Lum, Ms. Elizabeth Meahl, Ms. Karen Miyake, Mr. Alan Parker, Ms. Noemi Pendleton, and Ms. Sally Wehrsig. Critically important to this study were our key informants themselves who so freely and willingly gave their time and shared their expertise with us on ways to support eldercare in the Native Hawaiian community. We are also grateful to Mr. Clyde Namuo and Ms. Mervina Cash-Kaeo, who met with us earlier and helped us to understand many of the cultural implications to aging and caregiving. To Ms. Carol Matsumiya, secretary at the UH Center on Aging, we also sincerely thank for her editing expertise. Finally, we extend our appreciation to Dr. Yvonne Jackson and Ms. Meg Graves of the Administration on Aging for their continued support.

Mahalo nui loa.

Executive Summary

The purpose of this report is to share the findings from key informant interviews conducted in fall of 2007 by staff of Hā Kūpuna, the National Resource Center for Native Hawaiian Elders. Hā Kūpuna was established in the fall of 2006 with funding from the U.S. Administration on Aging. Under the leadership of Professors Noreen Mokuau, Colette Browne, and Kathryn Braun, it receives guidance from two advisory councils comprised of respected Native Hawaiian leaders and eldercare service providers. The goal of Hā Kūpuna is to develop and disseminate knowledge on the health and long-term care issues facing Native Hawaiian elders and their family caregivers in order to improve access to and delivery of services. Findings from this report will be used to guide Hā Kūpuna's activities in knowledge development and provision of training and technical assistance to improve the capacity of community organizations to deliver services and support families in caregiving roles. This study was strongly warranted due to the paucity of information assessing health status and long-term care needs for kūpuna in Hawai'i.

Key informants were contacted across the state of Hawai'i to share their perspectives on the health and long-term care needs of Native Hawaiian elders, those 50 years of age and over, and their family caregivers, as well as provide insight into their potential service preferences. Hā Kūpuna also assessed the challenges confronting the development and delivery of services to this population. These preliminary findings, in the order of the questions raised, are as follows:

1. Native Hawaiian elders served by these organizations have numerous economic, social, and health care needs.
 - **Health care:** Health care needs include chronic disease management, medical assistance, help with taking (and paying for) their medications, and knowing when to ask for help.
 - **Economic:** Many Native Hawaiian elders have low or inadequate income, with associated problems around paying "out of pocket" health care costs, and other issues related to housing, nutrition, purchasing medications, and services.

- **Social:** Elders want to be respected, live in harmony within their community, and not be perceived as a burden to their families. Increasingly, however, kūpuna are isolated and disengaged.
- **Families:** Families have three major needs: financial support; education and training on their caregiving roles, responsibilities, and issues; and specific support services (e.g., respite, home care).
- **System issues:** Elders and their families want a simplified system or help to navigate the present system. Policies to help families and caregivers stay involved could help with eldercare responsibilities.

Recommendations: Advocate for an adequate income for all that also includes an emphasis on financial literacy. Expand education and training options for all families. Create policies that support a holistic view of aging and the integration of economic, health, and mental health issues and inter-agency collaboration. Adopt a life course perspective (i.e., the realization that old age is the culmination of all that comes earlier in a life) around good health and health promotion. Improve family's abilities to access and navigate aging services and programs with a highly visible single point of entry for services.

2. In terms of preferences for care, Native Hawaiian elders want services that reflect their cultural values and choices.
 - Care should reflect Hawaiian traditions and practices.
 - Staff should be familiar and respect Hawaiian or "local" values.

Recommendations: Create or adopt policies that support workforce preparedness issues in elder care (i.e., increase the numbers of Native Hawaiians as health and long-term care workers and train all health care workers in Hawaiian protocol, values, and practices for those who work with Native Hawaiian elders and caregivers.

3. Kūpuna, similar to other older adults, hope to age-in-place and live independently or with family. However, they need quality and affordable services to do so. Those services identified most frequently include home health, day care, housing, Alzheimer's disease and related disorders specialty care, and Information and Referral. If services cannot be provided in a home or community setting, the need for long-term institutional care becomes more critical, and all islands expressed

shortages of such care. These services should be as home-like as possible, reflecting the national movement for a culture change in long-term care.

Recommendations: Identify Native Hawaiian caregivers and assess their needs. Advocate for the development and implementation of family centered policies and programs for elders (e.g., home health, home care) and services for families, both financial (payment for caregivers, assistance with home costs) and programmatic (e.g., respite, education and training for skill building). Build stronger interagency collaboration with those in the aging and disability networks.

4. Key Informants noted the care that families provide their elders, but also noted changes in family roles and responsibilities that conflict or compete with eldercare responsibilities—especially among younger generations. Key Informants believed that more data were needed to further explore this issue.

Recommendations: Expand policies that provide support to elders and their caregivers in all settings with concrete services and easily accessible information. Support research to examine projections around what family care will be available to elders in future years.

5. Also noted by Key Informants were a number of program and system needs that could improve the care for kūpuna. Not surprising, programs needed more funding, although other problems were noted (geographical barriers to care, better coordination, and increased focus on preventive services).

Recommendations: Develop and conduct research that identifies those evidence-based strategies that sustain families in saying engaged and providing the kūpuna with caregiving. Build stronger collaborative alliances with organizations that provide supports to caregivers such as the Executive Office on Aging Caregiving Network and caregiver training programs sponsored by Kapiolani Community College. Expand, create, and implement policies that help elders both live and die at home, and support the funding of a range of policies that provide for specific needs such as electric and transportation costs that can make a real difference in the lives of families. Advocate for the funding of affordable and accessible chronic disease management and health promotion programs that

integrate “best practice” findings from the research on Native Hawaiian health.

Future Needs and Directions:

This report summarizes the comments and proposes recommendations gathered from Key Informants who provide services to Native Hawaiian elders in the state of Hawai‘i. Individual variations exist in their comments; e.g., neighbor islands had more transportation problems compared to O‘ahu. Nonetheless, this report provides a thematic analysis in light of the literature on Native Hawaiian elder health and well-being. The following points speak to what we see as future needs and directions for kūpuna and caregivers in issues around health and long-term care.

1. **Health Profile and Need for Health and Long-Term Care Services.** Continued data collection efforts are needed to assess and document the health and long-term care needs of Native Hawaiian elders and their families living in Hawai‘i and the continental United States. Our assessment provides preliminary information from the perspectives of leaders in the Native Hawaiian community in Hawai‘i. It is equally important to hear from kūpuna and their families “in their own words”, including kūpuna who do and do not access these services, from kūpuna who represent different socioeconomic backgrounds, and from kūpuna and families on the continental United States.
2. **Roles of Kūpuna and the Family in Eldercare.** This report identified a number of needs to support families in providing care to family elders. Further study is needed to examine the role of kūpuna as they age and the role of culture in family responsibilities in eldercare. Historically, Hawaiian culture has provided great respect for kūpuna (Mokuau & Browne, 1994). Key informants raised a number of concerns regarding observations and changes in family care and the impact economics and values play in elder health and family caregiving roles and responsibilities. Projections about what family support Native Hawaiian elders may have access to in future years would be useful for long-term care planning purposes.
3. **Documenting “Best Practices” in Kūpuna Care.** Over the past ten years, an impressive body of work of Native Hawaiian scholars and organizations such as ‘Imi Hale have greatly enhanced the literature on

the impact of culturally responsive services for Native Hawaiians in health services such as smoking, cancer, and heart disease (Andrade et al., 1994; Blaisdell, 2002; Braun, Fong, Ka'ano'i, Kamaka, & Gotay, 2005; Hughes, Tsark, & Mokuau, 1996; Kaholokula, Braun, Kana'iaupuni, Grandinetti, & Chang, 2006; Mokuau & Braun, 2007; Mokuau, Hughes, & Tsark, 1995). This information should help to develop "best practices" in kūpuna services. Some ideas from this literature include: respect the culture with attention to values, protocol, and traditions; and involve and work with the elder's family. Further documentation of research will aid in guiding future elder services to help kūpuna to age-in-place and access and receive the services they need.

Health Promotion and Chronic Disease Management. The documented health profile of Native Hawaiians highlights the importance in providing services that keep elders in good health earlier in their lives. Increased support for health promotion, chronic disease management, and counseling programs in urban and rural neighborhoods that integrate Native Hawaiian health practices may have the best potential for meeting the health and long-term care needs of elders and families.

For more information

If you would like more information about this report or other Hā Kūpuna activities, contact:

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I. Introduction

Ola na iwi.
The bones live.

Said of a respected native elder who is well cared for by the family (Pukui, 1983, p. 272).

Elders in Native Hawaiian culture historically were recognized as major sources of wisdom and the transmitters of knowledge and training to younger generations (Mokuau, Browne, Braun & Choy, 2008). In ancient times (*wa kahiko*) and before western contact in 1778, the spoken word and the ceremonies of elders were the text of learning (Pukui, Haertig, & Lee, 1979, p. 57). In a symbolic ceremony called *hā* (breath), one's knowledge, wisdom, and training were transmitted by an elder breathing into the mouth of another person.

Much has changed since *wa kahiko*, but the importance of the transmission of values, knowledge, and skills from older to younger generations remains. Today, concerns exist for the nearly 65,000 kūpuna 50 years of age and over, living in the United States (U.S. Census Bureau, 2000). Documentation of these needs is strongest among these 41,000 kūpuna who reside in Hawai'i, while much less so among na kūpuna who reside in the continental United States. What we have learned about the health and well-being of kūpuna is cause for concern. In general, Hawaiian kūpuna have shorter life expectancies, poorer health, and greater disability than elders of other racial/ethnic groups in the state (Braun, Yang, Onaka, & Horiuchi, 1996; Kana'iaupuni, Malone, & Ishibashi, 2005). Other studies have found that Native Hawaiian elders exhibit poorer socioeconomic status and underutilization of some long-term care support services compared to their non-native elder counterparts in Hawai'i (Mokuau, Browne, & Braun, 1998). It would be reasonable to expect that kūpuna's higher social and health risks profile would lead to the use of more long-term care services. One of the few surveys conducted of Native Hawaiian elders found this not to be so; instead, caregivers, usually children and spouse, provided care to elders but with limited utilization of paid caregivers or other assistance (ALU LIKE, 2005).

Hā Kūpuna, the National Resource Center for Native Hawaiian Elders was established in the fall of 2006 with funding from the U.S. Administration on Aging. The name, Hā Kūpuna, speaks to the cultural practice of passing of *hā* (breath) from older to younger generations. In Native Hawaiian culture, it is believed that one's life essence, talents, and wisdom can be transmitted through the sharing of *hā*. Hā Kūpuna is under the leadership of Professors Noreen Mokuau, Colette Browne, and Kathryn Braun, and receives guidance from two advisory councils comprised of respected Native Hawaiian leaders and eldercare service providers.

The **goal** of Hā Kūpuna is to develop and disseminate knowledge on the health and long-term care issues facing Native Hawaiian elders and their family caregivers in order to improve access to and delivery of services. There are three primary **objectives**: (1) to establish a sustainable organizational infrastructure, (2) to begin to establish a national knowledge base on Native Hawaiian elders and their family caregivers focused on health and long-term care, and (3) to enhance the community's knowledge of long-term care and family caregiving through the dissemination of findings and the provision of training and technical assistance to professionals working with Native Hawaiian elders and their families.

The substantive work of Hā Kūpuna is in two fundamental areas: research and technical assistance. Priorities and plans for both areas were developed with input from the Native Advisory Council and Partner Organizations Advisory Council, with feedback from other key leaders in the broader community, and with information from the general literature (Mokuau et al., 2008). Our research agenda has a two-pronged focus: 1) an examination of historical influences on the resiliency and well-being of kūpuna, and 2) an assessment of contemporary health and long-term care needs, patterns, and preferences of Native Hawaiian elders and their family caregivers.

The purpose of this report is to share the findings from key informant interviews conducted in fall of 2007. In this study, Key Informants across the state of Hawai'i were contacted and asked to share their perspectives on health and long-term care needs of Native Hawaiian elders and their family caregivers, as well as to provide insight into their potential service preferences. Hā Kūpuna also assessed the challenges confronting the development and delivery of services to this population. The key informant interviews will be used to guide Hā Kūpuna's activities in knowledge development, training provision, and technical

assistance to improve the capacity of community organizations to deliver a range of services to support elders and their families in caregiving. We aim for *ola* (life and health) *pono* (to make right) *na kūpuna*, or ways to support a good life and health for our elders. For this report, we define older adults as those age 50 years and over. Long-term care is defined as the range of services that support the optimal health and well-being of elders.

II. Methodology

A. Key Informants

Key Informants were selected to ensure geographic representation, including the islands of O'ahu, Maui, Moloka'i, Kaua'i, and Hawai'i. Key Informants included executive directors of the five state-wide Native Hawaiian Health Care Systems, an executive director of one Title VI organization, and leaders of a rural hospital. For a complete list of the participants, organizations represented, and interview date, refer to **Appendix A**.

B. Data Collection Procedures

Hā Kūpuna's two advisory councils (the Native Advisory Council [NAC] and the Partner Organizations Advisory Council [POAC]), were instrumental in identifying key community leaders throughout the state with knowledge of Native Hawaiian elders and the health, long-term care, and other supportive services provided to them. These community leaders were then sent letters introducing Hā Kūpuna and requesting their participation as Key Informants. Once they agreed to take part, meetings were scheduled either at their offices or the University of Hawai'i at Mānoa, School of Social Work. In some cases, Key Informant interviews took place in a group context (i.e., multiple Key Informants at the same time) and others took place individually. All interviews were held during work hours and lasted approximately 1.5 to 2 hours. Key Informants who participated received a small *makana* (gift certificate) in appreciation for their time.

Key Informant interviews took place in late 2007 (October-December 2007, plus one in January 2008). After introducing the project staff participating in the meetings, the key informants were given background information on Hā Kūpuna. The Key Informants were then asked to identify the ways that their organization works with Native Hawaiian elders. Following this introductory communication, the interview was conducted in a semi-structured manner. Key Informants were asked a series of questions dealing with health and long-term care needs, preferences, and service delivery.

The researchers took extensive notes during each interview and were later typed into a recording sheet. All researchers who attended these meetings reviewed the

transcripts for changes and corrections. As a final step to assure accuracy and prior to data analysis, copies of the transcriptions were distributed to the Key Informant for any changes or corrections, and such changes were noted in the revised transcripts.

C. Study Design

Qualitative research is an appropriate method to study topics such as roles, relationships, social worlds, and culture (Rubin & Babbie, 2008). In general, the use of Key Informants, a common approach in qualitative research, utilizes questionnaires and interviews to obtain expert opinions from individuals who have special knowledge about the target population's problems and needs, as well as about current gaps in service delivery to that population. For this study, key informant interviews were appropriate because it was important to hear views on long-term care from major stakeholders in the Native Hawaiian community "in their own words" with a minimum of researcher bias. This approach also allowed for a qualitative research method, allowing the researchers to listen and record emerging concepts and group by theme.

D. Measures

Following a review of the literature on elder and caregiver needs and issues, the researchers developed a set of six questions that pertained to the health and long term care needs of kūpuna and their caregivers. These questions were standardized and open-ended, allowing the process to be consistent and thorough with a minimum of interviewer effects and biases. They included:

1. Can you describe how your agency works with older adults? Native Hawaiian older adults?
2. What do you think are the health and long-term care needs of Native Hawaiian elders?
3. What about the *'ohana* (family) of Native Hawaiian elders—are you aware of specific needs families may have in their abilities or willingness to provide care for their kūpuna?
4. Do you have any thoughts around what services and programs Native Hawaiian elders and their families may prefer, specifically in the areas of health and long term care?

5. Are these needs and preferences similar or different from elders and families from the general (non Native Hawaiian) population? If yes, can you provide us with some examples?
6. As an administrator, has your organization or agency experienced challenges/barriers to the development and delivery of services to kūpuna and their families?

III. Analysis

Our data analysis approach drew from the work of Strauss and Corbin (1990; 1994). Qualitative data analysis consists of discovering “plausible relationships proposed among concepts and sets of concepts” (Strauss & Corbin, 1994). We used three levels of qualitative data coding—open coding, axial coding, and selective coding—to allow us to break down the data, look for patterns, themes, or common categories, and develop some preliminary and tentative conclusions. The Key Informants were interviewed with a set of questions developed by the Hā Kūpuna researchers (see previous section on Measures) to identify the health and long-term care needs, issues, and preferences of older Native Hawaiians and their caregivers. Additionally, we asked these community leaders to identify their organization’s challenges or barriers to meeting the needs of older adults and their families.

Each of the six transcripts was read independently by the researchers to familiarize themselves with the raw data. This allowed for inductive analysis of the raw data. Following this independent reading, researchers met to discuss and identify the responses in the transcripts, and then to quantify those responses for which there was agreement. In the second step of analysis, Key Informant transcript responses were re-grouped by each question. Then, the frequency of responses to the questions was counted. From here, broad themes emerged. We then moved to axial coding, and began to merge the themes found in the open coding into subcategories. Finally, we turned to selective coding to think, refine, and integrate our final themes and explanations into the Discussion section of this report.

Similar to all qualitative studies, this study is designed to generate greater understanding and insight into the way people think, feel, and act. Hence, the use of words such as “most” or “few” are used sometimes to suggest a general shared opinion we observed and heard. These should be interpreted as broad directions.

IV. Results

In this section, we present the preliminary findings of our research, following the order of the questions as posed in the interview. We identify the key themes for each question based on Key Informant responses. Then, each theme is explained in more detail. Some themes are illustrated by quotes from the participants.

Question #1: Can you describe how your agency works with older adults? Native Hawaiian elders? Key Informants each spoke of their own program as it serves older adults. The Native Hawaiian Health Care Systems is a state-wide system with five sites that undertake health promotion and disease prevention strategies for Native Hawaiians to ensure that their clients get the services they need. ALU LIKE is a community-based health and social service organization serving Native Hawaiians of all ages. ALU LIKE and Hana Health Care are two Title VI programs funded by the Administration on Aging, U.S. Department of Health and Human Services, and Moloka'i Hospital is a private rural hospital and health care center serving the rural island of Moloka'i.

Agencies and organizations provided health care at different levels of interventions to all age groups including elders, and also participated in collaborative work with other agencies with and on behalf of elders (e.g., Dept. of Hawaiian Home Lands, Meals on Wheels).

Question #2: What do you think are the health and long-term care needs of Native Hawaiian elders? Key Informants stated that, similar to all older adults, there exists variability in Native Hawaiian elder health and long-term care needs (Hooyman & Kiyak, 2008). Five common needs of kūpuna were identified. These subcategories are: (1) health care needs, (2) economic needs, (3) social needs, (4) family issues, and (5) service issues.

Under **health care needs**, a major issue identified was the increased prevalence of chronic diseases and their disease management, whether at home, community, or institutional setting. Chronic diseases are long-term illnesses, rarely cured, that can challenge one's ability to remain in the community (Federal Interagency Forum on Aging, 2008). It is well documented that Native Hawaiians have higher rates of certain chronic diseases than other elders in the state; among these are heart disease, certain cancers, and diabetes. Other health needs discussed included medical assistance and medication insurance (how to

access care, how to pay for services, and how to pay for medications). Key Informants also expressed some concern that kūpuna do not ask their physician questions nor ask for *kokua* (help) when needed. Poor or lack of care was a concern; related to this was that kūpuna tend to have low access to the system, perhaps believing services do not help, are too expensive, and are not culturally-responsive or geographically accessible.

Kūpuna don't ask doctors questions and have anxiety about going to the doctor...need to improve relationships with their doctors.

Economic needs. Economic need was the second most common concern identified by Key Informants. One issue that respondents raised was the poor income status of kūpuna using their services. Poor income was related to numerous other problem areas; among them, adequate housing, good nutrition, service access, and transportation. Issues around who assists and controls the elder's financial resources were also issues. A related issue was the potential for financial exploitation.

Cannot afford to live, cannot afford to die, either.

[I] have heard of kūpuna who go to the hospital and when they come home, there are changes (e.g., financial control, home ownership).

Kūpuna lose autonomy over finances. We need to document their stories.

Kūpuna cannot afford the full dose (of medications) or "pharm" out pills to friends.

Social needs. Key Informants voiced many concerns about the needs of isolated kūpuna and had questions about who provides care when families are not able or willing to do so. Kūpuna long for *lokahi* (harmony) with their families and community, and yet many are not engaged with others and vulnerable to neglect and exploitation. Increasing information and referral, kūpuna specific activities (e.g., yard working), and consumer protection may improve program/service participation. Key Informants suggest that elders worry about becoming a burden to their families and feel guilty over imposing their needs upon busy family members. There was also a perception among some key informants that existing programs may not meet the social needs of elders (e.g., the idea among elders that some kūpuna attend programs just to “gossip”).

[We] have concerns over the isolated elders—those who do not have families around to help them, no one available to care for them.

Kūpuna need to be wanted by their families. A family bond provides a sense of purpose.

Family issues. Concerning family issues, a number of examples illustrated the appropriate care families provide their elders. What was acknowledged by many was that kūpuna want to live and die in their homes, and this requires family attention to do so. Caregiving was identified as having a huge impact on the family in numerous ways. For example, constant use of an oxygen machine and air conditioner (to make the room comfortable to one that is homebound) can result in high electric bills. Also identified were problems around family issues that impacted the health and well-being of kūpuna (discussed further in the following question). These family problems include neglect and substance abuse. Key Informants noted that some kūpuna are raising their grandchildren because the parents of the children are in jail or affected by substance abuse problems. Other comments suggested that the increased work and strain of caring for



“Kūpuna need to be wanted by their families.”

“A family bond creates a sense of purpose.”

grandchildren might have some negative impact on the health of kūpuna. The need for more data concerning this issue was voiced.

Many issues are unknown—families are reluctant to talk, but legal issues are critical and should be discussed before the funeral.

Don't see younger generations taking care of kūpuna during the day—it's paid service providers. It's rare to have families caring for their kūpuna because they lost the feeling of responsibility.

Service issues. A final subcategory in identifying elder needs concerns service issues. Similar to all older adults, kūpuna prefer to remain in a home setting—their own or their families' when vulnerabilities develop (State of Hawai'i, Executive Office on Aging, 2006). And, also similar to non-Native Hawaiian elders in the state of Hawai'i, shortages of services and assistance impact the health and well-being of elders (Hooyman & Kiyak, 2008). As a result of multiple and interacting vulnerabilities, there is increased need for services in the home (e.g., home care and home health, respite services), in the community (day services) and at the institutional level (long-term care beds). Other service needs mentioned were housing, an Alzheimer's unit or care, and transportation that are especially critical on neighbor islands. Also voiced was the need for updated information and referral services.

Kūpuna don't know about available resources—where to go for help.

They need daily assistance—transportation, keeping active, accessing specialty services.



“Many issues are unknown—families are reluctant to talk, but legal issues are critical and should be discussed before the funeral.”

“Kūpuna don't know about available resources.”

Question #3: What about the ‘*ohana* (families) of Native Hawaiian elders—are you aware of specific needs families may have in their abilities or willingness to provide care to their kūpuna? Three general categories of needs were identified: (1) system issues that can improve care (e.g., navigation, policy changes such as payment for caregivers), (2) need for family-supportive services such as respite, day care, and supplies; and (3) need for skilled personnel who provide the care as well as caregiver education and training for caregivers, and information and referral services.

Key Informants spoke of the changing nature of care. One respondent talked about his own family, and how he was chosen by his family to be the primary caregiver of his elderly aunt. Although caregiving was viewed as “women’s work”, he accepted the responsibility. Other needs raised included addressing family expectations, assisting families with realistic expectations about caregiving responsibilities, and helping families to stay engaged in care of their elder. Key Informants also raised concerns over the increasing responsibilities kūpuna have in caring for their grandchildren, as noted earlier.

The most significant problem facing problems is manpower for caregiving. Privacy is another concern—may only want a few people to handle physical contact.

Families help each other.

Ohana need more follow through, help families stay engaged.

If families are not in the health field, they don’t realize caregiving is time-consuming and involves gross things.

From a male perspective, don’t think it’s your kuleana (responsibility) to care for kūpuna.



“‘Ohana need more follow through, help families stay engaged.”

“Younger generations have a hard time taking care of kūpuna because they are busy caring for their own children or have their own problems.”

More troubling was the change noted in family values around the care of the aged. Service leaders expressed alarm and distress at the loss of interest, commitment, and *kuleana* (responsibility) by some families to care for their aged. A number noted changes in the family's cultural values and attitudes from earlier times (*wa kahiko*). These changes were attributed to a variety of causes. Some blamed economics, and having to work two or three jobs, leaving little time to provide care. For others, changes in cultural values related to kūpuna care were noted.

Younger generations have a hard time taking care of kūpuna because they are busy caring for their own children or have their own problems.

[We have] lost the (Native Hawaiian) value system. Do we need to teach Native Hawaiian values in schools like Kamehameha Schools since kids don't mimic their parents anymore?

Other Key Informants shared their thoughts on the best way to support caregivers. Suggestions focused on providing kūpuna the needed assistance and services remain independent and that in the end support the caregiver. Key Informants agreed on the need to do something for families—many who have unmet needs themselves and are strained by the added caregiving. A number noted that financial support could ease the stress, whether in caregiving employment policies or direct payments for caregivers.

[We] should spend the money on real services for kūpuna to give caregivers respite and assistance with meals. Poverty and subsistence living influence ability to provide care.

Question #4: Do you have any thoughts about what services and programs Native Hawaiian elders and their families may prefer, specifically in the area of health and long



“[We] should spend the money on real services for kūpuna to give caregivers respite and assistance with meals. Poverty and subsistence living influence ability to provide care.”

term care? One response was very clear among Key Informants: Elders prefer Native Hawaiian or “local” service providers. Kūpuna want services that reflect their Hawaiian cultural values, or at least reflect the local cultures of Hawai‘i. They request social and health care workers who understand and respect their culture, language and customs. One Key Informant added that, in a few instances, Hawaiian elders preferred services offered to the general population rather than kūpuna services.

Some kūpuna attend services where their peers go, and their peers are not necessarily Native Hawaiian due to growing up in Hawaii’s multicultural environment. Responsive services should acknowledge that kūpuna want to be surrounded by family as they are passing. They know when they are going (to die), and need family members to be around to pass the hā. Institutions do not have policies that support the family’s presence.

Key Informants also discussed that kūpuna want to age-in-place, and want to be respected. Suggestions here focused on ways to promote an environment that promotes such respect. One idea mentioned was the value of storytelling, or hearing their own voices telling their own life stories, as a preferred method of communication.

Kūpuna want someone to listen to them, to hear their voices. We should let them speak. [I] was inspired by a visit to a senior center in Alaska. They had a room for quilting and other activities. Also has a storytelling activity with kūpuna where a moderator would pose questions to imitative storytelling and then publish these stories. This provided a way of getting historical insight while keeping the memories of kūpuna sharp.

Question #5: Are these needs and preferences similar or different from other elders and families in the general (non Native Hawaiian) population? If yes, can you provide us with



“Responsive services should acknowledge that kūpuna want to be surrounded by family as they are passing. They know when they are going (to die), and need family members to be around to pass the ha. Institutions do not have policies that support the family’s presence.”

some examples? Key Informants answered this question with a “both and depends” response. The actual needs may not be different, but the way in which care is provided may be. A number of suggestions emerged. These can include increased support for practices associated with traditional Hawaiian healing and other ways to incorporate cultural practices into programs (e.g., foods, activities, engagement of family). Other comments were about the kūpuna’s desire to not be a burden to their families. While it is not clear how culturally specific this is, it does speak to the need to demonstrate respect, honor the culture, and listen to the voices of kūpuna.

The needs are not different, the way to meet the needs is different. For example, may offer different types of activities for Native Hawaiian elders to socialize. Service providers should either tie in or acknowledge the way it used to be for kūpuna —build respect.

Question #6: As an administrator, has your organization or agency experienced challenges and barriers to the development and delivery of services to kūpuna and their families? Key Informants all agreed that increasingly their limited resources (due to funding, geography, growing numbers of Medicare patients, and lack of skilled staff) are resulting in care that is not as coordinated as it could be, and that offers less emphasis on prevention. Meeting the need for long-term care beds is a difficult topic in some communities, particularly rural ones. A challenge faced by all administrators is to find the way to finance services given present funding sources. Other issues mentioned were needs of a legal nature, need for available and improved transportation, need for health screening funding, and need for data for more effective planning purposes. Responses from rural settings identified concerns about access to the numbers of adequately well-trained staff given current limitations with funding. Still another matter are the developing communities that displace local families to make way for wealthy ones, and the subsequent impact on cost and availability of housing, loss of the island life style, and diminishing social and health services.

V. Discussion

Ua 'ai au i kana loa'a.

Said with pride and affection by a parent or grandparent who is being cared for by the child he reared (Pukui, 1983, p. 305).

Drawing from the data, this conceptual frame around health and long-term care needs and preferences began to emerge:

1. Native Hawaiian elders have numerous health, economic, social, family and service needs. Low or inadequate income shapes many of these needs.
 - Health care: Native Hawaiian elders' health care needs include chronic disease management, nutrition, medical services, assistance in taking their medications, and knowing where and when to ask for help.
 - Economic: Many Native Hawaiian elders have low income and associated problems that concern housing, purchasing medications and services.
 - Social: Elders are increasingly isolated.
 - Families: Need financial support, caregiving education and training, and support services.
 - Services: Need for system change that simplifies the system, assists with navigating the social welfare and healthcare systems, and changing policies (e.g., employment policies that support family caregiving).

Recommendations: Advocate for an adequate income for all older adults and financial literacy for all. Expand education and training options for families in all settings. Create policies that support a holistic view of aging and the integration of economic, health, and mental health issues and inter-agency collaboration. Adopt a life course perspective (i.e., the realization that old age is the culmination of all that comes earlier in a life) around health and health promotion. Improve family's abilities to access and navigate aging programs with a highly visible single point of entry for services.

2. Native Hawaiian elders want services that reflect their cultural values and choices.
 - Traditions that reflect family care and spirituality of the aged in contrast to those values often viewed as more western values.
 - Traditions that promote values that accord respect to elders, build upon their strengths, and acknowledge their stories for present and future generations.
 - Staff awareness and knowledge of local or Native Hawaiian values can be strengthened.

Recommendations: Create or adopt policies that support workforce preparedness issues in elder care (i.e., increase the numbers of Native Hawaiians as health and long-term care workers and train all health care workers in Hawaiian protocol, values, and practices for those who work with Native Hawaiian elders and caregivers.

3. Kūpuna prefer to age-in-place and die-in-place. They want to live independently or with family, but need quality and affordable services to do so. Services most needed were identified as home health, chore services, respite, day care, housing, Alzheimer’s specialty care, and Information and Referral. If and when care cannot be provided in the home or community setting, a strongly voiced need was given for long-term institutional care in their communities. These services must be as home-like as possible, reflecting the national movement for a culture change in long-term care.

Recommendations: Identify Native Hawaiian caregivers and assess their needs. Advocate for the development and implementation of family centered policies and programs for elders (e.g., home health, home care) and services for families, both financial (payment for caregivers, assistance with home costs) and programmatic (e.g., respite, education and training for skill building). Build stronger interagency collaboration with those in the aging and disability network.

4. Key Informants acknowledged the caregiving that families provide their elders, and the challenges included increased stress, associated economic costs, and need for information and referral and education. Others noted changes in family roles and responsibilities, and had

questions about family commitment and abilities to care of the aged by families, particularly among the younger generations.

Recommendations: Expand policies and programs to support elders and their caregivers in all settings with concrete services that provide assistance and easily accessible information. Support research to examine projections around what family care will be available to elders in future years.

5. The leaders also identified a number of program and system needs that currently present barriers to optimal service delivery to kūpuna and their families. Limited funding is the primary problem (e.g., for health screening, long-term care services, and hiring of staff). Other barriers include lack of data for planning purposes, geographical barriers, need for increased coordination and collaboration, and limited focus on preventive care.

Recommendations: Develop and conduct research that identifies evidence-based practices to sustain families to stay engaged and provide caregiving to their kūpuna. Build stronger collaborative alliances with organizations that provide supports to caregivers such as the Executive Office on Aging Caregiving Network and caregiver training programs sponsored by Kapiolani Community College. Expand, create, and implement policies that help elders both live and die at home, and support the funding of a range of policies that provide for specific needs such as electric and transportation costs that can make a real difference in the lives of families. Advocate for the funding of affordable and accessible chronic disease management and health promotion programs that integrate “best practice” findings from the research on Native Hawaiian health.

Future Needs and Directions:

This report summarizes the comments and proposes recommendations gathered from Key Informants who provide services to Native Hawaiian elders in the state of Hawai‘i. Individual variations exist in their comments; e.g., neighbor islands had more transportation problems compared to ‘Oahu. Nonetheless, this report provides a thematic analysis in light of the literature on Native Hawaiian elder health and well-being. The following points speak to what we see as future needs

and directions for kūpuna and caregivers in issues around health and long-term care.

1. **Health Profile and Need for Health and Long-Term Care Services.** Continued data collection efforts are needed to assess and document the health and long-term care needs of Native Hawaiian elders and their families living in Hawai'i and the continental United States. Our assessment provides preliminary information from the perspectives of leaders in the Native Hawaiian community in Hawai'i. It is equally important to hear from kūpuna and their families "in their own words", including kūpuna who do and do not access these services, from kūpuna who represent different socioeconomic backgrounds, and from kūpuna and families on the continental United States.
2. **Roles of Kūpuna and the Family in Eldercare.** This report identified a number of needs to support families in providing care to family elders. Further study is needed to examine the role of kūpuna as they age and the role of culture in family responsibilities in eldercare. Historically, Hawaiian culture has provided great respect for kūpuna (Mokuau & Browne, 1994). Key informants raised a number of concerns regarding observations and changes in family care and the impact economics and values play in elder health and family caregiving roles and responsibilities. Projections about what family support Native Hawaiian elders may have access to in future years would be useful for long-term care planning purposes.
3. **Documenting "Best Practices" in Kūpuna Care.** Over the past ten years, an impressive body of work of Native Hawaiian scholars and organizations such as 'Imi Hale have greatly enhanced the literature on the impact of culturally responsive services for Native Hawaiians in health services such as smoking, cancer, and heart disease (Andrade et al., 1994; Blaisdell, 2002; Braun, Fong, Ka'ano'i, Kamaka, & Gotay, 2005; Hughes, Tsark, & Mokuau, 1996; Kaholokula, Braun, Kana'iaupuni, Grandinetti, & Chang, 2006; Mokuau & Braun, 2007; Mokuau, Hughes, & Tsark, 1995). This information should help to develop "best practices" in kūpuna services. Some ideas from this literature include: respect the culture with attention to values, protocol, and traditions; and involve and work with the elder's family. Further documentation of research will aid in guiding future elder services to

help kūpuna to age-in-place and access and receive the services they need.

4. **Health Promotion and Chronic Disease Management.** The documented health profile of Native Hawaiians highlights and demonstrates the importance in providing services that keep elders in good health earlier in their lives. Increased support for health promotion, chronic disease management, and counseling programs in urban and rural neighborhoods that integrate Native Hawaiian health practices may have the best potential for meeting the health and long-term care needs of elders and families.

Data Limitations

This study used qualitative methods to uncover the prevailing needs, issues and preferences in health and long term care of older adults, as seen by leaders in the Native Hawaiian health community. Results of this research are limited by small sample size and generalizability. Findings cannot be considered representative of all workers in the Native Hawaiian Health Care System, ALU LIKE, Moloka'i Hospital, Hana Health, or agencies that work with Native Hawaiian elders who were not interviewed. Finally, the views of elders themselves and their families were not solicited and are critical to develop future services.

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Appendix A: List of Key Informants

Name	Organization	Island Represented	Date of Interview
Billy Akutagawa, Judy Mikami, Kauai Manera, Jo Manaba, Donna Gamiao	Na Pu'uwai	Moloka'i	10-12-07
Janice Kalanihuia, Dr. Bill Thomas	Moloka'i General Hospital	Moloka'i	10-12-07
Cheryl Vasconcellos	Hana Health	Maui	10-25-07
Julie Oliveira	Hui No Ke Ola Pono	Maui	11-1-07
Joelene Lono, Donna Palakiko	Ke Ola Mamo	O'ahu	11-7-07, 1-15-08
Kaloa Robinson	Hui Mālama Ola Nā 'Ōiwi	Hawai'i	11-8-07
David Peters	Ho'ōla Lahui Hawai'i	Kaua'i	12-19-07

Appendix B: Native Advisory Council Members

- **The Honorable Daniel K. Akaka** (Honorary Chair), Senator, US Congress
- **Claire Hughes**, DrPH (Co-Chair), Retired nutritionist, Hawai'i State Department of Health
- **Kekuni Blaisdell**, MD, Professor Emeritus of Medicine, John A. Burns School of Medicine
- **J. Keawe'aimoku Kaholokula**, PhD, Assistant Researcher, John A. Burns School of Medicine
- **Shawn Malia Kana'iaupuni**, PhD, Director, Public Education Support Division, Kamehameha Schools

Appendix C: Partner Organization Advisory Council

- **John Tomoso**, MSW (Chair), Executive Director, Hui No Ke Ola Pono, Wailuku, Maui, former Executive on Aging, Maui County Office on Aging
- **Kealoha Takahashi**, BA (Vice Chair), Executive on Aging, Kaua'i County Agency on Elderly Affairs
- **May Fujii Foo**, MPA, Grants Manager, City and County of Honolulu Elderly Affairs Division
- **Sister Alicia Damien Lau**, MSN, MPH, COO of O'ahu Care Facility, Pearl City Nursing Home, and Kulana Malama
- **Wesley Lum**, MPH, MA, Assistant Specialist, University of Hawai'i Center on Aging
- **Elizabeth Meahl**, MPH, Director of Elderly Services, ALU LIKE, Inc.
- **Karen Miyake**, MS, Executive on Aging, City and County of Honolulu Elderly Affairs Division
- **Alan Parker**, BA, Executive on Aging, Hawai'i County Office of Aging
- **Noemi Pendleton**, MBA, Director, Executive Office on Aging, Hawai'i State Department of Health
- **Sally Wehrsig**, CAN, Caregiver Information and Assistance Specialist, Hawai'i County Office of Aging