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Listening to the Voices of Native Hawaiian Elders and ‘Ohana Caregivers: Discussions on Aging, Health, and Care Preferences

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Abstract

Native Hawaiians, the indigenous people of Hawai’i, are affected by varying social and health disparities that result in high prevalence of chronic disease, early onset of disability, and shorter life expectancy compared to other ethnic groups in Hawai’i. Six listening meetings were conducted, involving 41 community-dwelling kūpuna (Native Hawaiian elders) and ‘ohana

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(family) caregivers to investigate health and care preferences that offer the potential for improving well-being in later life for Native Hawaiian elders. As background, we provide three explanatory perspectives and theories—life course perspective, minority stress theory, and historical trauma—that guided the design of this study and provided the study's context. A number of overarching themes and subthemes were identified, some of which point to universal concerns with age and caregiving (such as challenges and costs associated with growing old and caregiving) and others that are culturally specific (such as influence of culture and social stressors, including discrimination, on health needs and care preferences). Results give further support to the urgency of affordable, accessible, and acceptable programs and policies that can respond to the growing health and care needs of native elders and family caregivers.

Keywords

Indigenous elders and caregivers; Health and long-term care; Native Hawaiians; Racial/ethnic elders

Introduction

Over the past two decades, increased attention has focused on the nation's disenfranchised racial/ethnic and cultural populations across the U.S. who are disproportionately affected by social and health disparities (U.S. Department of Health and Human Services [DHHS] 2010). These disparities are especially notable among people who are indigenous to the lands that currently comprise the U.S.—Native Hawaiian (NH), American Indian, and Alaska Natives. Similar to this nation's other indigenous populations, Native Hawaiians share a sociopolitical history of forced incorporation into the U.S. that has contributed to documented shorter life expectancies and higher prevalence of a number of chronic diseases in comparison to majority populations in the U.S. (Mau et al. 2009; Tsark et al. 1998; U.S. DHHS 2010).

Native Hawaiians are the indigenous people of the Hawaiian archipelago. In the U.S., they make up the largest subpopulation (46 %) under the Native Hawaiian and Other Pacific Islanders (NHOPI) label (U.S. Census 2010). Census data identified 1.2 million NHOPI in 2010, with 540,103 as "Native Hawaiian alone" and 681,182 as "Native Hawaiian in combination with one or more other races." Nearly 60 % of the nation's Native Hawaiians (450,000) reside in the state of Hawai'i. More than 36,000 Native Hawaiians are over the age of 60, with two thirds residing in Hawai'i and others residing primarily in California, Washington, Nevada, Utah and Oregon (U.S. Census 2010).

Available, albeit limited, data suggest that the health and care needs of Native Hawaiian elders far exceed the availability of services when compared to non-Hawaiian elders (Like 2005; Ka'opua et al. 2011a; Mokuau et al. 1998). Given their poor health profile, the reasons for their limited service use are unclear. The current study aims to address this research gap by investigating the health needs and care preferences of community-dwelling *nā kūpuna* (elders) and '*ohana* (family) caregivers in Hawai'i. We used six listening meetings to record elder and family caregiver perceptions around health and care needs and preferences, and the role of culture and other social determinants as influencers. We discuss three theoretical frameworks—life course perspective, minority stress theory, and historical trauma—that guided the development of our study design and provided a context from which to analyze and understand the disparities found in *nā kūpuna*. We present our results in light of these frameworks along with practice and policy recommendations.

This qualitative study is part of a larger, six-year, mixed-method design study conducted by Hā Kūpuna, National Resource Center for Native Hawaiian Elders in Honolulu, Hawai'i, that aimed to gain a full understanding of the social and health disparities faced by *nā kūpuna* (Browne et al. 2013). Established in September of 2006 with funding from the Administration on Aging, US Department of Health and Human Services, Hā Kūpuna is one of three congressionally mandated resource centers focusing on the health of native elders.

Literature

Increasing numbers of Americans are living longer, leading to the nation's changing demographic profile. The state of Hawai'i is no different, with nearly 15 % of the state's population 65 years of age or older (U.S. Census 2010). Although Hawai'i residents can claim the greatest longevity of all 50 states, not all residents live equally long or equally well. Hawai'i's older adult (60 years and over) multicultural population is approximately 56 % Asian (Chinese, Japanese, Filipino, Korean), 26 % White (non-Hispanic), and 6 % Native Hawaiian (State of Hawai'i, Department of Health, Executive Office on Aging 2013). The remaining 12 % are composed of other Asian, Native American, and African American elders (State of Hawai'i, Department of Health, Executive Office on Aging 2013). This smaller number of Native Hawaiians speakers to the fact that this population has one of the shortest life expectancies of these major ethnic groups in the state (Ka'opua et al. 2011a). On average, they live 10 years less than Chinese and Japanese elders, who have the greatest longevity of all the ethnic groups in Hawai'i. Native Hawaiians have higher mortality rates for cardiovascular disease and cancer than most other ethnic groups in the U.S. as well as their Japanese or Caucasian counterparts in the state (Ka'opua et al. 2011a. National data sets are hampered by the sample limitations found in most national-level surveys, but a recent examination of mortality among Native Hawaiians using the National Center for Health Statistics found similar increased mortality risks with Blacks (Panapasa et al. 2010).

Greater longevity, a key outcome measure to inform policy makers on the overall health of a group, is a triumphant result of improved public health measures, medical and technological advances, and increased awareness of the benefits of healthy lifestyles. Over the past 25 years, gerontological researchers have focused much of their attention on the impact of longevity on aging adults, families, and caregivers. Results are generally consistent. The great majority of older adults are cared for by family and friend networks, and many of these families and friend caregivers report feelings of caregiver burden and stress as well as satisfaction in meeting these responsibilities (Dilworth Anderson et al. 2002; Pearlin et al. 2005; Robison et al. 2009). Culture's influence on elder health and family caregiving has been investigated in White, African American, Hispanic, and to a lesser degree on American Indians (Dilworth Anderson et al. 2002; Turner-Goins et al. 2011b). Research with American Indian and Alaskan Native elders, although still in its infancy, suggests they receive much of their care from family and friends (John 1988; Korn et al. 2009). Data on

Hawai'i's indigenous (Native Hawaiian) elder population remains sparse. Of interest given their poor health profile are the influence of culture and the role of Hawaiian cultural values on health promotion and caregiving. These values include collective affiliation and interdependence of the individual, family, community, environment, and transcendent realms (Braun et al. 2004; Mokuau and Braun 2007). A Native Hawaiian core cultural value, similar to Native American values, speaks to the transcendent—the central role of spirituality and balance for health and wellness that surpasses what we see and know in the material world.

A number of culturally-based and culturally tailored programs have been developed and successfully tested to address the needs of Native Hawaiians with breast and colectoral cancer, diabetes, and heart disease (Braun et al. 2005; Ka'opua et al. 2011b, 2013; Look et al. 2012; Mokuau et al. 2012; Moy et al. 2010). Nonetheless, attention to the health needs and care preferences specific to *nā kūpuna* and family caregivers is at a nascent stage. Policymakers and public health officials committed to issues of health equity in native and other populations will be better equipped to respond to elder and caregiver needs with a clearer understanding of the interactions around age, culture, caregiving, health needs, and care preferences in later life.

Theoretical Perspectives

Researchers offer a number of explanatory and theoretical frameworks to understand the social, economic, and health profile of racial/ethnic populations. Among these are life course models, minority stress theories, and historical trauma (Thrasher et al. 2012).

Life Course Perspective—In earlier work, Hā Kūpuna researchers described the life course perspective and its use with the Native Hawaiian population (Browne et al. 2009). A life course perspective conceptualizes old age as one phase of life that is shaped by events and activities undertaken in the years leading up to old age. According to Halfon and Hochstein (2002), different health trajectories are the products of cumulative risk and resiliency and protective factors that operate in biological, behavioral, social, and economic contexts over time and impact health as the person develops and ages. For example, individuals with greater education earn more and have more resources to invest in curative and preventive care and healthier consumption (Galama and Van Kippersluis 2010). Additionally, aging is influenced by complex interactions between personal biography and sociohistorical and sociopolitical forces, resulting in different experiences of aging by ethnic, racial, economic and geographical cohorts (Elder 1994; Hatch 2005). For example, many Anishinaabeg elders (Great Lakes) born before 1940 were relocated from families to federal boarding schools where they were not allowed to speak their own language or practice their cultural traditions. Other federal policies of the time encouraged relocation of families to urban areas to work in manufacturing. Cohorts born after 1960 had a different experience, as the US government began reversing its assimilation policies and creating programs to help tribes develop tribally-owned business ventures (Jackson and Chapleski 2000).

Minority Stress Theories—Minority stress theories build on work on stress process models, which suggest that chronic stress (persistent and ongoing) as opposed to acute stress (occurring infrequently) generates psychological and physiological responses that accumulate over time to produce poor health outcomes (Lazarus and Folkman 1984; Segerstrom and Miller 2004). Stress can "arouse the adaptive machinery of the individual" (Pearlin 1999, p 396) or a community (Mokuau 2011). Lazarus and Folkman's stress and coping model argue that an individual's overall level of stress and consequent psychological reactions is influenced by an interaction between the initial assessment of stressfulness (appraisal) and availability of resources to mitigate the stressor (coping). Returning to our focus on the nations' racial/ethnic elder populations, research continues to document that their experience of chronic stress, including stress from discrimination, increased risk for a number of health disparities (Anderson et al. 2004; Barnes et al. 2004; Brondolo et al. 2009; Clark 2004; Jang et al. 2010; Pascoe and Richman 2009; Pearlin et al. 2005; Williams and Mohammed 2009). Meyer's work (2003), for one, extends stress theory by suggesting that stigma, prejudice, and discrimination over time create a hostile and stressful environment that causes mental and physical health problems and reduces preventive service use, and may be especially significant for racial/ethnic older adults (Dilworth Anderson et al. 2002; Hausmann et al. 2010; Ka'opua et al. 2011a, b; Son et al. 2007).

Historical Trauma Conceptual Model—Drawing on the conceptual work of Maria Yellow Horse Brave Heart (1998, 1999), Native Hawaiian and other indigenous health researchers consistently emphasize the influence of historical trauma and systematic discrimination and inter-generational marginalization on current health disparities (Kaholokula et al. 2009; Ka'opua 2008; Mokuau 2011). Sotero's Conceptual Model of Historical Trauma (2006) posits that subjugation of a population by a dominant group has a cumulative effect on the physical, sociocultural, political, and economic well-being of the oppressed group. The trauma may be felt first by first generation survivors (i.e., who directly experienced the traumatic effects) but is also felt by successive generations of their descendants (Ka'opua et al. 2011a, b). Hawaiian history is characterized as facing a number of adversities that followed western contact, resulting in the decline of the native population due to western diseases to which they had no immunity and eventually feelings of inferiority. As an example, to safeguard U.S. economic interests, the U.S. military overthrew the Hawaiian monarchy in 1893 (Apology Resolution 1993). Depopulation was accompanied by cultural degradation with the native language and many traditional practices outlawed and or subordinated (Bushnell 1993). The subsequent loss of Hawaiian sovereignty coupled with severe depopulation caused a collective grief among Hawaiian survivors (Kaholokula et al. 2009). Hawaiian health researchers link the poor health of Hawaiians in contemporary times to this cascade of adverse historic events and interventional social marginalization (Sotero 2006). Korn and colleagues found that caregiver stress was exacerbated in a Native American population experiencing historical trauma and intergenerational grief from colonization (Korn et al. 2009).

Methods

Design

We convened six focus groups – three with kūpuna and three with ʻohana caregivers in Hawaiʼi– to gather data on health and care needs and preferences. Because questions about health, illnesses, care, and quality of life have been found to be culturally defined and mediated (Andrulis and Brach 2007; Singleton and Krause 2010), we chose a listening study format, which is a culturally–informed focus group method (NCAI Policy Research Center and MSU Center for Native Health Partnerships 2012) to help tease out cultural beliefs, values, and motivations that have been identified to influence health needs and care preferences in younger Hawaiian populations (Mokuau and Tauiliili 2011). In addition to honoring culturally specific practices (i.e., for our study, beginning each group with a *pule* or prayer), listening studies encourage more time for elders to be “navigators of their own inquiry” (Braun et al. 2014). Thus, cultural values, beliefs or motivations are acknowledged as potential influencers on health and care preferences. We were guided by community based participatory research (CBPR) approaches and principles rooted in cultural competence with Native Hawaiian communities and a commitment to improved community health(Fong et al. 2003). The CBPR approach requires researchers to gain knowledge and cultural awareness of community health concerns through community-appropriate research instruments, and data collection and dissemination methods (Israel 2000). The Institutional Review Boards (IRB) of the University of Hawaiʼi at Mānoa and Papa Ola Lōkahi, the Native Hawaiian Health Care System, approved the study.

Sample

We hoped for 8 to 12 participants per groups. Participants were recruited by community-based programs on islands of Hawaiʼi, Molokai, and Kauai—the more rural islands of the state. These primarily rural communities were chosen because of the relatively higher proportion of Native Hawaiian residents. Partners included the State Executive Office on Aging; ALU LIKE, Inc.; the Native Hawaiian Health Care System on the islands of Hawaiʼi (Hui Mālama Ola Nā ʻOiwi) and Molokaʼi (Na Puʼuwai); and the County Offices on Aging on these islands. Inclusion criteria for kūpuna groups were Native Hawaiian (self identified), 60 years of age and older, cognitively alert, and willing/able to participate in a 1.5 h meeting. Inclusion criteria for ʻohana caregiver groups were Native Hawaiian (self identified) and providing unpaid care to an elder family member in the past 12 months. In all, 24 kūpuna and 17 ʻohana caregivers participated in the study. We hypothesize that the smaller caregiver numbers compared to kūpuna reflected results from different recruitment methods. Caregiver listening sessions with more robust numbers appeared to be related to our partnering with Native Hawaiian cultural guides who in turn requested study participation in face-to-face meetings. Recruitment methods that used individual invitational letters to prospective participants yielded much smaller numbers, even when co-signed by a community leader.

Measures

Our 90-min, semi-structured listening sessions were guided by a series of questions, but allowed the researcher freedom to probe beyond prepared questions. Our series of questions was informed by earlier research with key informants (Browne et al. 2009), as well as by members of our Hā Kūpuna Joint Advisory Council (JAC) and partners agencies. Initial questions were pilot-tested on the island of O'ahu, and minor changes were made in wording and question order. The final questions are listed in Table 1. Although kūpuna and ʻohana were convened in separate groups, the same question topics were used in both.

At the beginning of each listening session, participants signed consent forms, were informed of the study's voluntary nature, and had opportunities to discuss safeguards on confidentiality. They completed a brief demographic questionnaire, asking age, gender, community, and needs for assistance with care or caregiving. The primary researcher (CB) led the listening sessions while another researcher and/or student intern (PH) typed verbatim the participant responses on a computer. An LCD projector displayed participant responses in "real time" during the group session. This transcribing method, developed by the study's primary authors Braun and Browne, assures reliability of the data as participants could and did comment/correct what they saw as their verbatim comments on the screen. We note here that participant comments record verbatim reflect the common use of a form of "pidgin" English and are not edited by the authors. Participants were presented with a gift certificate for their time.

Data Analysis

Transcripts from the listening session were analyzed using the constant comparative method developed by Strauss and Corbin (1990). Two researchers independently coded the transcripts, using open coding, axial coding, and selective coding. Beginning with open coding, we independently read the transcripts to familiarize ourselves with the raw data. This step allowed us to begin identifying patterns and themes. The common coding system developed from this step ensured consistency and reliability. Following this identification, the research team met to discuss coding systems, and categorization of responses were discussed until we reached consensus. This step ensured accuracy of the qualitative data analysis in capturing all key issues. We then turned to axial coding, where we regrouped transcript responses by group questions. From here, we identified and merged the broad themes. We also identified quotes to illustrate the range of opinions and comments to support the identified themes (Curry et al. 2009). Finally, we used selective coding to think, refine, and integrate our final themes and subthemes. Following the principles of CBPR, a draft report was presented to our Hā Kūpuna JAC for review and as a check for external validity. Council member recommendations included language clarification, cultural contextual information, and format changes for better appreciation of the study findings.

Results

Participants

The three kūpuna sessions included 21 females and three males. The age range was 60 to 94 years, with a mean age of 77. Of the 24, 15 (63 %) graduated from high school or earned a GED, and eight (37 %) had some college. Elders appreciated assistance with cooking, cleaning, shopping, paying bills, and, going to the doctor. However, few needed help with bathing, dressing, eating, or getting in and out of bed. All by one elder (who used a paid caregiver), received assistance from a spouses or adult child.

The three ‘ohana sessions included 11 females and six males. The age range was 38 to 77 years, with a mean of 57 years. Nine (53 %) of caregivers were employed outside of the home; 11 had completed high school, and 6 had some college. Of the 17 ‘ohana caregivers, more than half (8) of the ‘ohana members were caring for parents, 7 were providing care to a spouse, 2 for a sibling, and 1 each for an uncle, grandparent, and cousin respectively. Nearly half (7) of the 16 ‘ohana caregivers were caring for multiple persons at the same time; most commonly a parent and a spouse. They reported providing 2 to 24 h of care per day. Most frequently, they helped the elder with shopping, going to the doctor, cooking, cleaning, bathing, medications, and paying bills. On average, they had been providing care for 7 years (range 3–10 years).

Because the comments from the kūpuna and ‘ohana sessions were very similar (nor did they differ by geography), thematic data are presented for the 41 participants as a whole. Results are organized around the eight study questions.

The Concept of Kūpuna: How Do You Define a Kūpuna?

Elder and ‘ohana caregivers spoke positively about the concept of kūpuna [elderhood] and the role of kūpuna in their families and in the Hawaiian culture. Common descriptive terms from both groups of participants spoke of the wisdom that comes with age (“a kūpuna is knowledge,”) (“when someone has experience in life”) and referred to the sharing of knowledge (“a kūpuna is one who teaches”). A number of participants associated kūpuna with issues of cultural preservation (“I feel responsible for both the older and younger generations—it is the Hawaiian way”). Echoing a similar comment, another stated “kūpuna … pass down culture, religion, values, in the right way to the next generation” and “kūpuna looks to the past and future. Kūpuna are the ones with the knowledge—wisdom. They respect Hawaiian values and deserve respect.” Participants suggested that kūpuna was a term closely connected to grand-parenthood, and kūpuna in all groups provided care to their mo’opuna (grandchildren). However, there were mixed comments on whether this was a positive thing. On one hand, we heard: “When I think of kūpuna, I think of grandparents—I think of love. They have so much patience and love”. On the other hand, we also heard this comment from an elder “…you feel like kūpuna when they pile up the kids on you” and this one:

> Kūpuna would like to enjoy life, but family comes first. They stay home to care for mo’opuna (grandchildren) while [adult] children work. Can’t enjoy life. Can’t come to center because they have to babysit. (81 female elder)

Interestingly, while some attributed the term kūpuna to physical attributes (“white hair”), others commented that they thought the word “kūpuna” referred to any older person, not just a Hawaiian elder. And, while some commented that the term was related to age (“more and more, you 70 and 80 you are getting old—you are kūpuna”), one 66 year old female kūpuna did not agree with this interpretation and held this diverse connotation:

> People say by age but I don't' think so. You can be young and be a kūpuna. 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 kūpuna. It's not the Hawaiian way [to equate age with kūpuna] —it's a western way.

What are the Health Needs of Native Hawaiian Kūpuna? How Can We Keep Kūpuna Healthy?

This question elicited a range of responses, centering on these three: 1) a healthy diet, 2) adequate income, and 3) accessibility to specific health and support services to stay at home. For many, eating healthy was not only important but also equated with Hawaiian culture and diet. Many commented on the importance of taro[1] and poi[2] for physical, emotional, and spiritual health ("taro—it's part of medicine") and ("Poi—it's our bread and butter"). Poi was viewed as spiritual, in, "It's not just food—it is the spiritual connection to poi—the source," and "We eat a lot of poi and that's very healthy—if we want our mana'o (spirit), that's where it is." 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]."

Participants in every group emphasized the importance of an adequate income. Both kūpuna and ʻohana caregivers commented on the challenges of growing old and the expenses of providing care. While Hawaiian culture emphasizes care of kūpuna ("… as Hawaiians, when you grow up, you take care of kūpuna"), the financial demands of caregiving were noted as daunting. Responses ranged from the costs related to kūpuna 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, one ʻohana caregiver stated: "I quit school to care for mom but I worry when she becomes bedridden—how will I pay to get her nursing?" Another 68 year old'ohana caregiver participant shared this:

> … 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 [better] instead of hospitalized. Hawaiians are proud, once you take things away pride is hurt.

The third commonly heard need focused on the accessibility of services to older adults—specifically, caregiver education, respite, and transportation services. However, what was also noted was the importance of an acknowledged diversity among kūpuna. Although some participants voiced their comments through a cultural lens, other did not, noting that "not all kūpuna alike," and "services have to be the right fit," and "Everyone has different kind of personality. People who know the kūpuna well should find the best fit programs that would fit their needs—individual needs not dependent on their ethnicity or culture."

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[1] Taro, or kalo is a staple food that supplies starchy-carbohydrates calories and vitamins and minerals in the diets of kanaka maoli (Hawaiian ancestors) as well as many present-day Hawaiians. According to Dr. Claire Hughes, kalo was viewed as kino lau (body form) of the god Kane (Hughes, C. (2013)). Keeping the gods close. *Ka Wai Ola*, Mei (May), 30, 5. p.16.

[2] Poi is a highly nutritious starch, somewhat similar to a potato, made by mashing the kalo (taro) plan's corm, or root. Among Native Hawaiians, it is considered a highly important and sacred part of Hawaiian life.

How Do We Keep the ‘Ohana Caregiver Healthy? Are These Needs Specific to Native Hawaiians?

This question elicited the most engaged responses in both sets of groups. Participants understood that caregiving was provided by families of all racial/ethnic backgrounds, and acknowledged that ‘ohana caregiver faced a multitude of needs in the provision of care—health, financial, emotional, culture, and service-related. Both kūpuna and caregivers commented on the commitment and time needed to provide care of kūpuna. Many caregivers shared their own health concerns—arthritis, diabetes and heart disease—that at times interfered with caregiving and led to ‘ohana isolation. A number of families discussed the emotional and financial challenges related to balancing work and caregiving and not being able to afford the care that could meet some of their needs (“Day care is good but expensive”). One 48 year old male’ohana caregiver shared:

> I am lucky 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. No choice, my main purpose is mom. I signed up for chore, 1.5 years later, got it. Helps. But faster process would help. Long wait. Lot of sacrifice. Job wise it hurt me. But fortunate, my manager understand. Being burnt out, no extra help.

Others talked about the many emotional challenges to caregiving as with this comment from a 77 year old male caregiver:

> My wife—incurable disease. Hard at first, especially first 23 years. I have come to learn—and settle down. With this…it boils down to love, respect, caring. It is hard at first, expensive, you have to tone yourself down. Anger management, too. Needs helps with meds, shopping, driving. Other things she can do—wants to do. She is 77 years old. Hard, hard work. I am not kūpuna, or caregiver. I am just a responsible husband.

Participants stated that elder and ‘ohana needs are the same as all elders and caregivers, native or non-native (“we all grow old”, “aging is universal”, “caregiving is hard”). However, such comments on the universal nature of caregiving were contradicted with what we heard from many others that were specific to the Native Hawaiian community: diet and the importance of specific cultural foods such as taro and poi for well-being, the important role kūpuna play in the family and in cultural preservation, the family’s commitment and responsibility for eldercare, and the integration of spirituality as a coping mechanism (“*Spiritual support? It is the only way*,” and this one: “*I pray, I read the bible*”). Other comments spoke to the need for culturally-knowledgeable service providers. For most of the participants, it was best if the care provider was Hawaiian or knew Hawaiian ways and respected Hawaiian culture. In contrast, a smaller number suggested that the ethnicity of personal assistants was irrelevant, as long as the person had the skills to provide appropriate care.

Another need of ‘ohana caregivers was long-term care supports such as caregiver education and support services (“we need [education] since we are doing the caregiving”), respite care, and transportation. One 43 year old ‘ohana caregiver explained:

> I wish they have programs for us like classes. Like health and nutrition. At [my] Aunty' house [program staff] came in and helped us. Teaches me to go shopping and pick healthier foods. But they stopped that.

Other ‘ohana caregivers discussed the importance of learning more about aging processes and coping strategies to deal with sometimes difficult and demanding situations. For instance:

> My wife diagnosed with breast cancer. She wanted to keep working, company let her leave, chemotherapy, radiation and drip, it was hard, 44 years married, and this happened 5 years ago. We made commitments to your spouse, you do it (63 year old male ‘ohana caregiver).
>
> I take care of mother. Trying to learn what she needs, at first keeping up with changes, you get this automated line, frustrating! (43 year old male caregiver)

Who Should Provide Care to Elders—a Family or Government Responsibility?

Caregiving was viewed as a shared responsibility (kuleana) of the family and government. The majority of respondents said the government should have a role in taking care of elders and families, especially in making insurance and medications more accessible and affordable. One 63 year old male ‘ohana caregiver stated:

> Medical insurance so confusing, especially part D. What does in 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 wrestle with all of this information.

A few participants felt that government care goes against the family's *kuleana* (responsibility) to care for its elders, but the majority of participants disagreed, noting that caregivers need assistance to give care. Geographic location was viewed as a determining factor in not using services. Participants from these rural sites shared that service accessibility and transportation was problematic. The majority of the respondents turn to friends and families for help, illustrating a core Hawaiian value of family and extended networks.

We attempted to draw out more specifics about family and intergenerational transfers to uncover financial and other resources provided to elders from their families. Unmet needs can help identify gaps in services and care. We asked the question in this way: Think about a close friend who is Native Hawaiian, 65 years or older, and who has adult children still living. Does this kūpuna receive any emotional support [visits, phone calls], in-kind support [help the family provides with housing, transportation, and medication], or financial support from his or her family? We worded the question in this way to avoid the shame of having to admit to a stranger [the researchers] that a child does not care enough to provide support. This is especially important in family-centric cultures (Mokuau and Tauiliili 2011). Respondents told us that friends and families helped—the support networks were an expanded one. In general, responses agreed that emotional help was provided, in-kind help was at times provided, and financial help was rarely provided if at all. One respondent stated that it is sometimes the adult child who is depending on the kūpuna for financial support, not the other way around.

Barriers to Care: Positive or Negative Experiences with Caregiving

We heard multiple reasons why kūpuna and caregivers do not use services even when eligible, available, and/or accessible. The primary theme from both sets of groups was that family members *do* provide care—it is the family kuleana. Comments from both elders and caregivers identified four major care barriers: (1) real or perceived costs of services; (2) agency rules and regulations; (3) issues around respect and privacy; and (4) limited specific services.

Elders and caregivers spoke of the costs of care, and ʻohana caregivers complained of the high costs of caregiving, and the competing demands placed on families to balance work and family responsibilities. Many discussed the high cost of health care and health insurance that made services and medications unaffordable. A few participants stated that Hawaiians are less affluent and so their children are less likely to be able to take care of kūpuna. As most of the listening sessions 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. Additional barriers to care focused on housing—the expense of housing and the unavailability of affordable housing (“Housing is as crisis. Always filled—everybody need more kūpuna housing”). And this example from a 70 year old female elder:

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

The second identified barrier was around agency rules, regulations and policies that were confusing to elders and family caregivers members alike, and, more importantly, were perceived to be insensitive to Hawaiian “ways.” Participants discussed that kūpuna and families may not know about services, and a number wondered why caregivers could not be paid to provide family caregiving (“they pay strangers—why not families?”). We also heard angry comments from those who had used other programs, with statements around intrusive admission/eligibility procedures, disrespectful staff, and inflexible rules and regulations that lead to discontinuing the service. Income eligibility rules were often voiced as unfair. A number of participants noted that family income is counted for service eligibility, often leaving the elder ineligible, as in these examples:

> You go to the food bank, and they ask you how many in your family. It doesn’t matter, the number of family, so where are we Hawaiians? We are on the bottom. It’s not being distributed to Native Hawaiians. (66 year old female kūpuna).

> My mom doesn’t qualify for anything, yet she can’t afford to pay for the services she needs. Lots of middle class kūpuna falling through the cracks because don’t qualify but you can’t afford—that needs to change; can’t get respite, other services. (77 year old female ʻohana caregiver)

Na kūpuna and ʻohana caregivers alike made references to a gap group; people who are not poor enough to qualify for government assistance but are not wealthy enough to make it on their own. Those in this group are technically overqualified for governmental assistance. An aspect of the gap group issue that is unique to Hawaiians was raised by a number of respondents. Many kūpuna do not realize that their names are on old family land titles due to a complicated history with Hawaiian homestead and other land titles. While these kūpuna do not receive any revenue from such lands, they are disqualified for assistance because the lands continue to be counted as liquidable assets.

> Many elderly people don't even know but their families own land so they don't quality for financial benefits. Welfare, food stamps. Forced to sell that place. Not even able to remove their name from the property. Lots of homeless Hawaiians because of that. (65 year old elder).

Additional comments referenced insensitive service providers and the ways in which agency rules and regulations are implemented. As one stated: "Requirements say, only spend 1 h with client. Limited by the rules, hard to explain. Administrators need to hear from clients." Another voiced her frustration and stated:

> They make you feel like dirt… Questions don't pertain. They want to know I was only $2.00 over [eligibility criteria] and got nothing. Tried to get disability … said he wasn't handicapped enough, he was in a wheelchair, and he had medications. So never mind already, I don't need help. (66 year old caregiver).

The third theme centered on na kūpuna and ʻohana—their sense of pride, and their needs for respect and privacy that too often were not met by service providers. Participants from both kūpuna and caregiver groups described the importance of respecting kūpuna, and how not providing respectful care resulted in loss of elder pride. One caregiver stated that "Hawaiians are a proud people..once you take away, pride is hurt." As another ʻohana caregiver explained:

> 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. Family talking about putting aunty in home, but here I take care of mom. We are taught that as [Hawaiian] children. (92 year female) Service providers may ask once, and if get "no" they then go on to next question. Lost opportunity"[to learn something important]. (77 year old female ʻohana caregiver)

Participants in all groups voiced distress around their experiences with agency and hospital staff that were perceived to be insensitive and disrespectful to kūpuna. This lack of respect resulted, according to one participant, as to why kūpuna do not return for needed services ("Turned away many times so won't use"). Caregivers noted that increasing dependencies sometimes lead to an elder's reluctance to ask for help due to feelings of guilt and pride ("kūpuna demoralized—cannot do but want to do"). Kūpuna were also reluctant to burden their children, as in this comment: "I feel guilty asking my kids to help." Returning to issues of pride, both kūpuna and caregivers spoke on the values of pride and independence as they relate to accepting help from others. One caregiver stated it this way: "force them to be dependent, because things that would allow them to be independent are not available; loss of pride, worth, no choice," and these comments that spoke to disrespectful care by service providers: "lack of staff compassion, don't make you feel you are so poor, you need me." Another shared this:

> Our people do not want to expose private details and are reluctant to tell problems. 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. Turned away, just out of disrespect. So rude, no respect. Because she’s poor, and handicapped. Nobody deserves to be treated like that. (72 year old female ‘ohana caregiver)

We also heard similar comments (“People in cities use services, but people in country, old Hawaiians won’t,”) and this comment that speaks to the sociocultural history of Hawai’i:

> Plantation era. Worked hard. Too much pride to ask. I can take care of myself. Too much questions (agencies), I don’t want to answer. I just want help. It’s private. (70 year old female elder).

What Programs or Services Do You Prefer and Use, and Why?

Although kūpuna and caregivers shared comments about their negative experiences with inflexible rules and regulations, uncaring/insensitive staff, and limited services, they also commented on positive experiences and the services they preferred. A number of participants expressed specific appreciation for culturally tailored services from the Native Hawaiian Health Care System and Alu Like offices on their respective islands. They also identified the helpful services offered by the one-stop shop on the Island of Hawai’i’s area agency on aging. An aging conference was viewed to be very helpful by one caregiver: “This conference really helped me, taught me things”. Another caregiver shared this:

> Medicare is not enough. Education is needed, sometime they angry. My dad has Alzheimer’s Disease, died at 88 years 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 all ages, don’t wait until the need for caregiving starts. (63 year old male caregiver).

Elders and families enthusiastically shared opinions about the services and programs that were preferred and used. Both ‘ohana and kūpuna noted that service accessibility, while usually confusing, was made easier when one became familiar with a community service through a neighbor or friend. It also helped that, once connected, they developed a trusting relationship with a staff member. Other service preferences identified were agency personnel who were culturally informed, professional staff that made home visits, services that were affordable, and organizations whose policies and procedures were respectful and not intrusive. (i.e., privacy issues). Helpers most often were referred to as nurses or social workers. Services that would be preferred if available and affordable are respite (“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” and: “kūpuna get isolated and sad—transportation can help”). 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, staff need respect” and this one: Communication is easier [with a Hawaiian]. Another hopefully stated: Hawaiian doctors coming home, maybe they can work here. A number of participants spoke to the dual influences of cultural values and history, as in this comment from a 70 year old kūpuna:

> [Hawaiians] Proud people. Grew up with an inferiority complex, some haven't been able to climb out of the puka (hole in ground). (70 year old female kūpuna).

There were 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." And this one: "Have to start at younger ages [to be healthy]. In this center, a nutritionist helps. That we can access …a good thing to fund." More health promotion and prevention programs were also suggested, as hear in: "More and more elderly women with breast cancer. More prevention and screening. Some never had mammograms" and positive comments about the culturally-tailored and valued nutrition program on the island of Maui.

Discussion

Knowledge about the health and care needs of native elders and their caregivers is slowly increasing but still in a nascent stage (Browne et al. 2009; Korn et al. 2009; Lewis 2011; Turner-Goins et al. 2011a, b). This limited attention may be due to the small size of these populations, but their critical health profile and the nation's commitment to issues of health equity demand more research on native elders. We engaged elders and ʻohana caregivers in listening meetings to respond to this research gap and to learn more about Native Hawaiian elder and family caregiver experiences with aging, health needs, and care preferences. Results can help to deepen the understanding of policy makers and public health officials to the importance of cultural values, beliefs, and stressors as key variables in the design and delivery of programs and services for older adults and ʻohana caregivers.

Similar to national data sets, our study sample of kūpuna and ʻohana caregivers were primarily women (National Alliance for Caregiving and AARP 2004), relatively educated (e.g., high school or better), and physically independent. Kupuna stated that they primarily receive care from an adult child or spouse, although it was the spouse who "helps the most." The types of help received were supportive in nature—shopping, cooking, cleaning and transportation. Caregivers stated their primary care recipient was often a parent or spouse, following by other relative and adult child. The most common areas for providing assistance were reported as similar to the kūpuna responses—shopping, transportation, cleaning, cooking, medications and paying bills. More than half of caregivers were employed outside the home. Nā kūpuna and family caregivers identified elder needs around maintaining a healthy diet, having an adequate income, and accessibility for specific support services. Nā kūpuna and caregivers noted the emotional and financial burdens associated with caregiving and recognized barriers to accessing services. Both sets of participants explicitly and implicitly identified a number of care preferences that are grounded in Native Hawaiian core cultural values. Families sought help from other family members and government programs, and yet were troubled by what was perceived as nonresponsive organizations, rigid regulations, and at times less than respectful agency and service personnel.

Two overarching themes emerged: the myriad of challenges and costs associated with growing old and caregiving; and the dual impact of core cultural values and social stressors (i.e., discrimination as perceived in disrespectful care and services) as influencers in elder and caregiver needs and preferences. Within each theme, we also identified subthemes that are both universal to aging and culturally-specific (see Table 2). Finally, we linked these findings to the theoretical frameworks discussed earlier in this paper.

Challenges and Costs of Growing Old and Caregiving—Our findings are similar to other national studies that identified the emotional and financial challenges of growing old and caregiving (National Alliance for Caregiving and AARP 2004). The high costs of food, health care, and services were identified needs in every listening session. ‘Ohana caregivers spoke of their own emotional and health needs, and the difficulties in providing financial support to elders due to the competing demands of family and work, another universal concern. Na kūpuna were sensitive to these needs as well. Families are not opposed to public and private services but often found them unaffordable due to limited finances. Specific to Hawaiian families, kūpuna face additional program eligibility challenges due to lower socioeconomic status of Native Hawaiians and land title documentation based on historical land laws, blood quantum, and other factors. For the most part, families want to provide care, but need financial and service supports from a mix of family and government services to do so. Preferred services for caregivers included respite, transportation, and caregiver education and support. The care preferences shared by our sample were similar to those identified in other native and non-native elders and families (Korn et al. 2009; Pearlin et al. 2005). Although elders and families welcomed accessibility to services because this help allowed them to take care of their responsibilities, they were frustrated with operational barriers set up by agencies and organizations to service delivery. These included agency and financial rules and regulations, disrespectful staff, and intrusive admission and eligibility processes (i.e., privacy issues). We heard many comments from participants about service providers’ disrespect to kūpuna and to ‘ohana, and in general staff insensitive and unknowledgeable to Hawaiian culture.

Core Culture Values, Stressors, Health Needs and Care Preferences—Although participants in general stated that aging was a universal experience, they also spoke positively and often of the many Native Hawaiian core cultural values around caring for kūpuna and the role of elders in cultural preservation. In direct contrast to a western view of aging as one associated with decline and disease, participants described kūpuna as filling a respectful role in the family and Hawaiian culture. In work with American Indians, researchers have also identified similar core values on the role of elders in cultural preservation and for family obligations in elder care (Jervis et al. 2002). Hawaiian culture is family centric, and participants viewed the family as the preferred caregiver although governmental support via programs was acceptable. However, how help is offered and received may also be influenced by traditional values of kokua (help/support) that suggest it should be provided without being asked. Participants spoke about prayer and spirituality as coping mechanisms for both kūpuna and caregivers, the importance of cultural dietary preferences (i.e., taro and poi) and culturally responsive and tailored services, and the importance of respect and honoring privacy issues in elder communication. Cultural issues were also expressed in how we conducted these focus groups (e.g., participants corrected us when we would neglect to begin or end a listening session with prayer). Taken together, these findings provide insights into the primacy of culture in native elder populations that have been reported by other researchers with American Indian elders (Fingerman et al. 2011; Korn et al. 2009), and Alaska Native elders (Lewis 2011).

But we also heard that *nā kūpuna* experiences with aging and the ‘ohana’s caregiving experiences were negatively impacted by stressors associated with stigma, discrimination, and poverty (“no respect, need dignity”, “Hawaiians at the bottom”). Similar findings have been found in work with other native caregiver populations in the U.S. (Korn et al. 2009; Scharlach et al. 2006), and provide support to the minority stress theory discussed earlier. Participants in both kupuna and ‘ohana caregiver groups commented on the issue of poor service delivery, often a part of the health and long-term care debate (Lehning and Austin 2010). But specific to Native Hawaiians, we heard many cultural concerns—specifically, the lack of knowledge of Hawaiian culture and “local” values and practices by service providers. One respondent shared how his mother’s new worker came into the house wearing her shoes and not calling his mother a respectful name. His mother refused to have the worker return. Meyer’s stress model is helpful here, as it offers a unique perspective to this study that incorporates discussions on stressors such as stigma and discrimination but that also pay attention to the strengths in the community and within the individual and his/her culture that we heard in identified care preferences. Our kupuna participants, and many of our ‘ohana caregiver participants as well (many of whom were also 60+ years of age), grew into adulthood during the plantation era and before the Democratic Revolution of 1959. This was a period of plantation oligarchy, race was associated with class, Hawaiian language was banned from use in schools, intense labor strife, and Native Hawaiians at best were tracked into technical and menial jobs. Life course perspectives help us see these sociohistorical events as important “shaping” experiences. Many government programs played a negative role and were defacto agents of social control. It is not hard to see how older Native Hawaiians perceive workers in a negative light.

What alarmed us was what was not discussed—namely, the health risks and shorter longevity of Native Hawaiians. Those diseases and conditions that are more prevalent among Native Hawaiians include chronic diseases and conditions—cancers, cancers, diabetes, asthma and obesity—all of which result in increased care needs and dramatically shorter life expectancies (Ka’opua et al. 2011a). All participants readily discussed the increasing health needs of *nā kūpuna* with age that result in increased family expectations to provide caregiving. ‘Ohana also spoke freely of their own health issues. However, neither *nā kūpuna* nor caregivers were knowledgeable about the health risks that are more common in Native Hawaiian elders compared to their non-native aged counterparts in Hawai’i or about and their shorter life expectancies. We are not sure if participants did not want to share this information with us, were not informed that Native Hawaiian longevity is the shortest among the five major ethnic groups, or lacked knowledge on how poor health practices (i.e., diet) can contribute to poor health. We also wonder if life priorities reflect cultural views on what may be associated with quality of life from a more traditional Hawaiian perspective, an area of needed future study. Regardless, we believe this lack of knowledge is a barrier to care and accessing and incorporating preventive care measures.

As supported by life course perspective, the poor health of Native Hawaiians throughout their lives points to the need for health education and primary health care over the life course. In addition to cultural expressions around seeking help and support, we also suspect that the negative experiences shared in these sessions have influenced their willingness to seek out and use services. Participant comments spoke of core Hawaiian values around aging and caregiving but also about their experiences with stigma and perceived discriminatory behaviors. Similar to the work of Korn et al. (2009) with American Indians, our results suggest that participant health needs and care preferences exist within a “cultural backdrop of historical trauma and intergenerational grief arising from the colonization experience” (p. 375).

These results underscore the importance of culture and cultural factors in aging and caregiver experience but also identify potential stressors related to stigma and discrimination that are linked to health and care preferences. Future research on aging, health and racial/ethnic elder populations should focus on both the resiliencies found in cultures around elderhood, cultural preservation, and caregiving, and the influences of history and other social determinants (e.g., economics, discrimination) in understanding and meeting elder and family needs.

Practice and Policy Recommendations

There are numerous federal, state, and private sector organizations and services working to provide elder and family health and support services to promote independence, support family in caregiving tasks, and potentially delay institutionalization. In each listening session, elders and ‘ohana caregivers identified services that they would like to see more available—respite, transportation, and caregiving education and support. They also wanted to see sensible and sensitive organization rules and regulations, more staff education and competence to Native Hawaiian issues, aging issues, and caregiving concerns. Universities may offer coursework in aging, but many professionals in the field remain untrained, and this is especially true in the area of cultural competence. Service organizations that work with older adults and families should be informed of culturally and linguistically informed and relevant standards for cultural competence and adhere and commit to their implementation. A useful framework is provided by the new revisions to the National Standard for Cultural and Linguistic Appropriate Services (CLAS), developed by the Department of Health and Human Services Office of Minority Health (Office of Minority Health 2013). This blueprint is intended to promote respectful care by helping organizations improve health care quality in serving the nation’s diverse populations.

To determine if kūpuna and ‘ohana caregiver needs are in fact being met, organizations will do well to review their own service mix in the communities for which they serve. One area of focus could be on strong role of elderhood and family centeredness of Hawaiian families, suggesting that organizations provide services that in turn continue to strengthen family obligation. Given the financial challenges in these communities, support to kūpuna and caregivers could also include financial support. Programs funded through Title VI of the Older Americans Act, ACL/AoA are in alignment with national directions to help elders age in place and the concerns of native communities, and are available in many native communities. Returning to the theoretical work discussed earlier, we suggest that the merging and integration of concepts from life course, minority stress theory and historical trauma can help to educate professionals and public health officials about how to better respond to native needs and care preferences by listening to their recipients. Practices that are both culturally and historically informed and that promote respectful and responsive care are urgently needed and have the best chance for impacting eligibility, access and service utilization.

This study should be replicated so that its primary limitations—small sample size and limited generalizability—can be addressed. We note that a more robust sample size would allow findings to have a greater impact on policymakers and public health professionals who serve Native Hawaiian elders on both the continent and Hawai'i. Our kūpuna and caregiver inclusionary criteria (that they be physically able to attend a 1.5 h focus group) resulted in a relatively high functioning sample, which may have contributed to responses that reflect a more independent and active lifestyle. Because participants were recruited through agencies, many were familiar with some services, and this may have influenced their answers. It will be useful for future studies to also enlist participants with more varied backgrounds; i.e., education, economic status, and health functioning to help tease out the influence of these variables on health and care preferences. Finally, more attention should be provided to study recruitment methods, some of which clearly worked better than others. For example, as discussed earlier, partnering with community cultural guides or leaders resulted in a more robust group size compared to recruitment attempts that mailed out individually addressed invitational letters to prospective participants, even when such letters were co-signed by community leaders.

Nonetheless, a number of universal and culturally specific needs and preferences were identified. While access to affordable health and long-term care services and supports are essential components for work with any elder or caregiver group, work with *nā kūpuna* and 'ohana caregivers also spoke to needs and preferences that reflected core Native Hawaiian values and the stressors related to stigma, poverty and discrimination. The generally poor health profile of Native Hawaiian elders only emphasizes the importance of identifying needs and preferences that take into account both universal concerns and those that are mediated by age, culture, history, and perceived discrimination.

Conclusions

A total of 41 elders and caregivers participated in these listening discussions. Nā kūpuna hope to age in place with respect, and 'ohana caregivers hope to continue to provide care with help from affordable, accessible, and culturally informed support services and education. We drew from theoretical models and frameworks as a first step toward increasing our understanding of Native Hawaiian health and care preferences that can translate to more effective policies and practices. Results from this study support the continued need for culturally tailored and affordable programs, as well as additional research given the heterogeneity within Native Hawaiians, a changing cultural milieu, and generational and other changes. More recently, attention is being directed to those services that demonstrate cultural safety, an issue of growing importance to indigenous populations living in the boundaries of nations other than US. (Mokuau 2011). A stronger articulation of these frameworks may help professionals enhance their understanding of native cultural values and social determinants and stressors that impact health needs and care preferences in Native Hawaiian and other racial/ethnic and minority elders.

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Table 1

Kupuna and Ohana caregiver questions

1. What is your name, and how do you define a kupuna?
2. What are the health needs of kupuna, and how can we keep kupuna healthy? Are the needs of Native Hawaiian elders different or the same from other elders in our community?
3. How do we keep the ‘ohana of kupuna healthy? Are these needs different or the same from other non-Hawaiian caregivers?
4. 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?
5. Can you tell us about any positive or negative experiences with services?
6. Think about close friend who is 65 plus and who has adult children still living. Does this kupuna receive any of the following from his/her family:
    a. Financial assistance
    b. Emotional assistance/support
    c. In-kind support (e.g., housing, help with getting and taking medications).
7. Are you aware of any programs or services that are preferred (e.g., chosen, used) by kupuna and their families? What are your thoughts on the reasons for this?
8. Is there anything else you would like to share on this subject?

Table 2

Summary of themes

Response category	**Responses specific to elders and family caregivers, or both**		
	Elders	**Caregivers**	**Both**
Primary Themes			
Challenges and costs of growing old and caregiving			
Responsibilities of “grandparenthood”	X		
Limited knowledge of Native Hawaiian health profile			X
Importance of healthy diet, adequate income, access to care			X
Experience with service barriers-rules and regulations			X
Experience with service barriers-disrespectful care			X
Core cultural values, stressors, health needs and care preferences			
Importance of cultural values in service design and delivery; diet, prayer and spirituality, staff trained in cultural competence.			X
Kūpuna as cultural preservation for family and community			X
Specific health worries; increased frailty	X		
Specific stressor unique to Hawaiians related to access			X
Preferred family support programs-family caregiver education, respite services, and transportation		X	