

Patient Educ Couns. Author manuscript; available in PMC 2009 February 1

Published in final edited form as:

Patient Educ Couns. 2008 February; 70(2): 281–291.

# Pacific Islanders' Perspectives on Heart Failure Management

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## **Abstract**

**Objective**—To identify the health beliefs, attitudes, practices and social and family relations important in heart failure treatment among Pacific Islanders.

**Methods**—Four focus groups were convened with 36 Native Hawaiians and Samoans with heart failure and their family caregivers. Thematic data analysis was used to categorize data into four domains: health beliefs and attitudes, preferred health practices, social support systems, and barriers to heart failure care.

**Results**—Common coping styles and emotional experiences of heart failure in this population included avoidance or denial of illness, hopelessness and despair, and reliance on spiritual/religious beliefs as a means of support. **Among study participants, more** Samoans preferred to be treated by physicians whereas **more** Native Hawaiians preferred traditional Hawaiian methods of healing. Two types of social support (informational and tangible-instrumental) were identified as important in heart failure care. Barriers to heart failure care included poor knowledge of heart failure, lack of trust in physicians' care, poor physician-patient relations, finances, dietary changes, and competing demands on time.

**Conclusion**—The recruitment, retention, and adherence of Pacific Islanders to heart failure interventions are affected by an array of psychosocial and socio-cultural factors.

**Practice Implications**—Interventions might be improved by offering participants accurate and detailed information about heart failure and its treatment, engaging the extended family in providing necessary supports, and providing tools to facilitate physician-patient relationships, among others, within the context of a larger socio-cultural system.

## **Keywords**

Heart failure; patient education; treatment adherence; Pacific Islanders

# 1. Introduction

Heart failure is a leading cause of death and disability in the United States (US) that currently affects more than 5 million Americans (1). Evidence suggests that the burden of heart failure varies across ethnic groups, with African-Americans and Hispanics suffering poorer quality

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of life, more frequent hospitalizations and decreased survival compared with Caucasians (2-4). However, less is known about the burden of heart failure among Pacific Islanders. Native Hawaiians and Samoans are the two largest Pacific Islander groups in the US (5). According to the 2000 US Census, 534,443 Native Hawaiians and Samoans (full or part) live in the US, the majority in the state of Hawaii where Native Hawaiians, Samoans, and other Pacific Islanders together comprise more than 23% of the state's total population (5). Although heart failure prevalence data is not yet available for Pacific Islanders, both of these Pacific Islander ethnic groups share a similarly high prevalence of heart failure risk factors, such as hypertension, diabetes, and alcohol and drug abuse, compared to other ethnic groups in the US (6,7).

In a study that categorized Asians and Pacific Islanders as a single ethnic group, Asian and Pacific Islanders with heart failure had longer hospital stays and underwent more medical procedures than Caucasians (8). However, when compared to Caucasians and Asians, Pacific Islanders have higher rates of heart failure risk factors, including hypertension, heart disease, and obesity (9-11). Indeed, when Asians are compared to Caucasians in the absence of Pacific Islanders, Asians and Caucasians with heart failure had similar heart failure outcomes (12, 13), suggesting that Pacific Islanders may experience greater heart failure burden than both Asians and Caucasians.

Patient education is a cornerstone of heart failure therapy and has been shown to significantly improve outcomes, including hospital readmissions and mortality, compared with standard medical care alone (14-16). Education on diet (e.g., sodium restriction), fluid restriction, taking multiple medications, weight monitoring and symptom self-management are key components of a successful program, particularly when family members (the primary source of physical and emotional support) are included (17,18). However, most treatment outcomes studies were done predominantly among Caucasians and, to a lesser degree, African-American patients with heart failure. Little is known about heart failure care among other U.S ethnic groups, especially Pacific Islanders.

People from certain ethnic groups may have unique cultural factors affecting the management of their heart failure, such as health beliefs and practices that are not consistent with the medical model and its prescribed lifestyle changes (19-21). Such differences could influence heart failure treatment choices and subsequent outcomes (13). Certain ethnic groups also face socioeconomic barriers to heart failure care, such as poor access to healthcare and insufficient medical coverage (22-24). As a result, it is assumed that culturally-tailored health interventions are more effective **than standard interventions** (25). Several culturally-appropriate interventions for the management of other chronic illnesses have been developed and found effective for African-Americans, Hispanics, and Native Americans (26-28).

Pacific Islanders, such as Native Hawaiians and Samoans, with heart failure could benefit from culturally-tailored heart failure interventions that incorporate their unique health beliefs (e.g., illnesses as a form of retribution) and practices (e.g., prayers and use of herbal remedies) that stem from traditional Pacific Islander healing practices and spirituality (29). Pacific Islanders also face socioeconomic barriers to managing a chronic illness, such as poorer access to health care (30-32). Thus, heart failure interventions based entirely on Western notions of health and well-being (e.g., separation of mind and body, absence of spirituality) may not be as effective as culturally-tailored heart failure interventions.

Recognizing the need to improve the heart failure care of Pacific Islanders, the *Mālama Pu'uwai* (Hawaiian for "caring for the heart") *Study* was initiated to develop and implement a culturally-tailored heart failure intervention. To inform the design of this heart failure intervention, we sought to identify factors **in heart failure care** that might influence the

recruitment, retention, and adherence of Native Hawaiians and Samoans, the two large Pacific Islander groups in the U.S. (33), to such an intervention from their own lived experiences. Specifically, we examined health beliefs, attitudes, practices and social and family relations important in heart failure care among Native Hawaiians and Samoans with heart failure and their family caregivers.

# 2. Methods

# 2.1. Study design and theoretical framework

Focus groups with Native Hawaiians and Samoans with heart failure and their family caregivers were convened to complete the objective of our study. The focus group methodology was employed because it is consistent with the tradition of Pacific Islanders who prefer to share their experiences orally and face-to-face (vs. surveys or telephone interviews), allowing them to judge the researcher's intent and trustworthiness as information is shared (34-36).

The theoretical constructs common to most health behavior change models served as the underlying theoretical framework in developing focus group questions and in data interpretation. These constructs are health beliefs and attitudes, (e.g., self-efficacy, locus of control, spirituality), health practices (e.g., treatment preferences and coping strategies), and social (e.g., type of family supports) and environmental factors (e.g., access to care) affecting help seeking behaviors and treatment adherence (37,38).

# 2.2. Recruitment and participants

We recruited Native Hawaiians and Samoans from rural and urban communities to increase representation and diversity within our sample. Native Hawaiians and Samoans were our target Pacific Islander populations because they comprise the majority of the Pacific Islander population in Hawai'i and the U.S. (33). We conducted 4 focus groups: Two focus groups (n = 17 people) among Native Hawaiians from a homestead community; 1 focus group (n = 7) among Samoans who were clients of an urban community health center; and 1 mixed Native Hawaiian and Samoan focus group (n = 12) from a rural community. Family members and patients with heart failure were included to more fully assess the range of perceptions and attitudes toward heart failure.

Three Pacific Islander health care workers (1 Samoan and 2 Native Hawaiian) assisted in recruiting participants from their respective communities and convening the focus groups. Two of the recruiters were affiliated with a community health agency and one recruiter was affiliated with a Native Hawaiian homestead organization. Ethnicity and heart failure diagnosis was based on participants' self-report and verified, in most cases, by their reported use of medications consistent with the treatment of heart failure. However, a minority of participants reporting heart failure could not remember the names or types of medication they were prescribed.

# 2.3. Procedures

We designed open-ended questions (see Tables 2 and 3) to probe participants' health beliefs and attitudes, self-care practices, barriers to adherence, and the role of family and social supports in managing their heart failure. The four specific domains of interest were 1) health beliefs and attitudes, 2) health practices, 3) family and social supports, and 4) barriers to heart failure treatment.

Focus groups were convened in the participants' respective communities, and each group took approximately two hours to complete. About half-an-hour was spent on informed consent, completing a short demographic questionnaire, and introductions of group members. Before

questions were posed, a prayer by an elder in the group, an explanation as to why we were conducting the focus group, and a brief explanation about heart failure were given. Approximately 1½ hours were spent on actual focus group discussion. All focus groups were led by the same trained facilitator (with the assistance of a co-facilitator) to ensure consistency of facilitation. All groups were conducted in the English language with the exception of the Samoan-only group, which utilized a bilingual translator. In addition to recording responses on flip charts during the group discussions, all groups were audio recorded for later transcribing. All participants received a \$20 gift card to a local store as an incentive.

# 2.4. Thematic data analysis and summary

We analyzed focus group data using a thematic data analysis technique (39). The audio recordings of the focus groups were transcribed verbatim by a trained medical transcriber for analysis. Thematic analysis began with a review of the transcripts by two independent reviewers to extract themes across the four domains of interest. It was decided *a priori* to extract and compare focus group themes by groups rather than by individuals because an individual's responses can be influenced by the responses of other group members and not necessarily reflect previously held ideas or beliefs. Reviewers extracted themes based on 1) their mention in the focus group, 2) their elaboration or endorsement by other members in the group, and 3) their mention in at least 3 of the 4 focus groups.

One of the transcript reviewers was a health professional who assisted in conducting the focus groups; the other was a health professional who had no involvement in the focus group under review. After themes were identified by the reviewers, they met as a group along with the focus group facilitator and co-facilitator to discuss the identified themes and their placement within the four domains of interests. Themes that were similar in nature were aggregated into a single representative theme.

# 3. Results

# 3.1. Participants' Characteristics

As summarized in Table 1, of the 36 participants, 30% were adults with heart failure and 70% were family members who provided home care to a Native Hawaiian or Samoan person with heart failure. Two-thirds of all participants were Native Hawaiian. Four of the participants were family members not of a Pacific Islander ancestry, but who provided heart failure care to a Native Hawaiian or Samoan person. Approximately half (55%) of the participants with heart failure were women, although women made up a majority (84%) of the caregiver participants. A majority of participants had a high school diploma or greater. Heart failure participants were older and married (73%) while caregivers were younger with 52% married and 20% never married.

# 3.2. Heart failure beliefs and attitudes

To identify themes relevant to heart failure beliefs and attitudes, we asked: "How do you feel about having (or caring for someone with) heart failure and what you are being asked to do to manage it?" and "What do you think would happen if you (or your family member with heart failure) followed your (his/her) doctor's recommendations fully?" Four themes were identified: 1) avoidance and denial of illness, 2) hopelessness and despair, 3) religious/spiritual faith, and 4) trust in physician's care. These themes and their representative quotes by type of participant —heart failure patient or caregiver—are listed in Table 2.

Participants expressed that they or their loved ones with heart failure often "avoid" or are in "denial" of their illness either out of fear of having heart failure or lack of understanding about the illness. Participants spoke about a sense of hopelessness and despair in having heart failure,

and many alluded to the idea that people with heart failure are simply "biding" their time. As a result, the participants expressed a strong reliance on their spirituality and Christian beliefs to deal with the uncertainty of their or their family members' illness and the idea that heart failure outcomes are influenced by the "will of God".

Trust in physician's care was also identified as a theme, but notable differences were observed between Native Hawaiian and Samoan participants. Native Hawaiians expressed a mistrust of physicians and Western-based medical care, commenting that their physicians "don't care" about them, are "too busy" to listen to their concerns, are not forthcoming with them and do not give enough medical information, and prescribe medication without advising them of potential side-effects. Samoans, in contrast, expressed confidence in their physicians' medical care, commenting that one reason they trusted their physician was because Samoan church leaders have emphasized the importance of following their physicians' medical advice.

# 3.3. Heart failure treatment practices

To identify themes relevant to heart failure treatment practices, we asked: "How would you (or your family member with heart failure) prefer treating or managing your (his/her) heart failure?" and "Besides what the doctor is asking you to do, is there anything else you (or your family member) are doing to manage your heart failure?" Five themes were identified: 1) preference for physician's care versus traditional cultural healing practices, 2) diet and exercise changes, 3) stress management, 4) subsistence lifestyle, and 5) prayers/faith in God. These themes and their representative quotes by type of participant—heart failure patient or caregiver—are listed in Table 2.

We found notable differences between Native Hawaiian and Samoan participants in their heart failure treatment preferences. Samoans preferred being treated by a physician for heart failure versus traditional Samoan healing practices. In contrast, Native Hawaiians believed that traditional Hawaiian methods of healing, such as *lomilomi* (Hawaiian therapeutic massage) and  $l\bar{a}$  'au lapa'au (use of Hawaiian medicinal herbs), might be just as, if not more, effective in treating heart failure than Western medicine.

Both Native Hawaiian and Samoan participants endorsed lifestyle measures as important in the management of heart failure, such as eating less salt and fat, getting more physical activity, and reducing stress. For stress reduction, they mentioned the use of meditation exercises, deep breathing techniques, and *lomilomi* as methods for dealing with their stress. Another lifestyle measure endorsed by both groups was that of subsistence living. They expressed that a subsistence lifestyle (e.g., growing their own fruits and vegetables) might help in adhering to the dietary restrictions of heart failure, given the cost of fresh foods and their infrequent availability. Samoan participants stated that a change from their traditional diet in Samoa (based on a subsistence lifestyle) to a Western lifestyle in the U.S. (e.g., processed and fast foods) has negatively impacted their ability to manage their diet because they do not have adequate land to grow their own foods and processed foods are often cheaper.

Religion/spirituality was another theme that emerged from the focus groups. Consistent with their religious/spiritual beliefs, Native Hawaiians and Samoans reported relying heavily on prayers (mostly Christian) as a means of managing (i.e., grace of God) and coping with their illness. A reason Native Hawaiians preferred traditional Hawaiian healing methods over Western-based medicine was due to the emphasis on spirituality (e.g., the medicinal herb worked because of one's belief in God and in the medicine's power) in the traditional methods.

# 3.4. Family and social supports

To identify themes relevant to family and social supports in managing heart failure, we asked: "What kinds of support from family, friends, and the community are most helpful in caring for your (or your family member's) heart failure?" The identified themes described 2 types of social supports needed by both heart failure participants and caregivers: 1) informational support and 2) tangible-instrumental support. These themes and their representative quotes by type of participant—heart failure patient or caregiver—are listed in Table 3. We defined informational support as the provision of information, advice, and perspective and tangible-instrumental support as offer of goods and services from one person to another (40).

Informational support was identified as an important type of social support in managing heart failure. Participants expressed that their family members can best assist them in managing their illness by knowing more about heart failure and how it is treated, and in assisting with medication and symptom management. Tangible-instrumental support was also identified as a type of social support in which participants expressed wanting family members to help and share in the care giving responsibilities (e.g., accompanying participants to doctor's appointments, preparing meals). Participants also stated that family cohesiveness was important in heart failure care.

Caregivers' need for information and tangible-instrumental support was another theme that emerged from the focus groups. Caregivers, like participants who had heart failure, also believed they needed more education about heart failure. Participants who were caregivers expressed a strong need for respite or temporary relief from their care giving duties. Many of the caregivers were the only family member providing any sort of care to their loved one with heart failure despite the presence of other adult family members in the home. They expressed that the sharing of the care giving duties amongst family members was needed to avoid "caregiver burn out."

# 3.5. Barriers to heart failure care

To identify themes relevant to barriers in heart failure care, we asked: "What are some of the barriers to following your doctor's recommendations and making changes?" and "What are some of the barriers experienced by the person you are caring for in following his or her doctor's recommendations and making changes?" Six themes were identified: 1) lack of knowledge about heart failure, 2) lack of trust in physicians (Hawaiians only), 3) poor doctor-patient communication, 4) financial burden, 5) difficulty in making dietary changes, and 6) competing demands on time. These themes and their representative quotes by type of participant—heart failure patient or caregiver—are listed in Table 3.

The participants strongly expressed that a lack of knowledge about heart failure and its management was a significant barrier to managing their heart failure or that of their loved ones. They believed that their healthcare provider did not spend adequate time getting to know them as a person, and often did not adequately explain many things about their heart failure, such as its cause, symptoms, and medications (e.g., why they were taking them and their adverse side-effects). This belief appeared stronger among Native Hawaiian participants and contributed to their mistrust toward physicians.

Other heart failure treatment barriers identified were financial burdens, dietary changes, and competing demands on time (e.g., childcare, work, family obligations). A financial burden for many of the participants was the cost of medications and healthier food choices versus lowercost but less healthy food items, such as canned and processed foods. Such foods also created a barrier to making needed dietary changes as many of the participants expressed that it was difficult to give up processed and fast foods. Finally, participants, mostly caregivers, expressed

that competing demands on their time, such as child/grandchild care and work responsibilities, were barriers to heart failure care.

# 4. Discussion and Conclusion

#### 4.1 Discussion

We sought to identify the health beliefs, attitudes, preferred treatment practices, family and social supports, and barriers affecting heart failure among Native Hawaiians and Samoans. To our knowledge, this is the first study to examine heart failure care among Pacific Islanders. Given the dearth of available information, we employed focus groups to learn from the lived experiences of Native Hawaiians and Samoans with heart failure and their family caregivers. The focus group is a method of inquiry that is culturally-acceptable to Pacific Islanders and a necessary approach when little is known about a complex phenomenon.

In our attempts to identify the health beliefs and attitudes held by Native Hawaiians and Samoans with heart failure, we found that they spoke more to their coping styles in dealing with, and their emotional experiences of, heart failure. A common coping style identified among Native Hawaiians and Samoans was that of avoiding or denying the presence of their heart failure. Avoiding or denying an illness is found to be a type of passive coping style (e.g., escape-avoidance and distraction coping) among people with heart failure (41,42), and is associated with the reporting of greater physical symptoms of heart failure compared to people with more active coping styles, e.g., problem-solving and support seeking (43). Our participants gave two possible reasons why Pacific Islanders with heart failure would choose to avoid or deny their illness. One reason was a fear of having heart failure and the other was a lack of knowledge and understanding about the diagnosis. It is common for people with heart failure to report a lack of knowledge and understanding of their illness, despite receiving regular medical care, and this may affect their self-care behaviors (e.g., recognizing and managing physical symptoms) and cause psychological distress (44).

Some Pacific Islanders, especially older adult Polynesians, may also choose to avoid or deny their illness because of traditional Polynesian beliefs about misfortunes and the power of the spoken word. A common Polynesian belief is that to speak of something could give it *mana* (power and life) and thereby manifest or exacerbate the problem (29). We cannot ascertain, based on our data, that this is the motivation for some of our participants' avoidance or denial of their heart failure diagnosis, but it certainly warrants further investigation.

A sense of hopelessness and despair was identified as a prominent emotional experience of Native Hawaiians and Samoans with heart failure. Hopelessness and despair are essential features of certain types of depression among people with a chronic disease (45). As one participant commented, many Pacific Islanders with heart failure are simply "biding" their time, suggesting that they may not have a sense of control over their illness and its outcomes. Another participant summarized the sentiment of many others by noting that heart failure was seen as a "constant burden" in their lives, both from the perspective of those with heart failure and the family caregivers. Depressive symptoms, such as hopelessness and despair, among people with heart failure are serious concerns given that an association between depressive symptoms and increased heart failure morbidity and mortality has been consistently observed (46-48). Moreover, depressive symptoms are associated with passive coping styles in people with heart failure which in turn have been associated with poorer outcomes (41,42).

Given the emotional impact of heart failure, Native Hawaiians and Samoans relied heavily on their spirituality and religious faith as a source of strength and support. The role of spirituality or religious beliefs in affecting health outcomes is not yet fully understood. However, studies of people with heart failure have found that greater spiritual well-being (e.g., greater meaning

and peace) is associated with less depression (49) and better quality of life (50). It is not clear whether or not greater spiritual well-being leads to better treatment adherence among people with heart failure (51). Nevertheless, spirituality and religious beliefs among our sample of Native Hawaiians and Samoans appear to serve as another coping mechanism for dealing with the emotional and physical burdens of heart failure.

We also learned that family support was very important to Pacific Islanders in effectively managing their heart failure. Studies have found that family support and size of social network are associated with depressive symptoms in people with heart failure and heart failure outcomes, such as hospital readmissions and mortality (52-54). The importance of family support in way of informational (e.g., knowledge of heart failure) and tangible-instrumental (e.g., preparing meals and driving to medical appointments) supports were most frequently mentioned by study participants than other types of social support (e.g., companionship and appraisal). Studies have found that a lack of informational support, along with not living with family, is associated with more psychological distress among elderly people with heart failure (55) and poorer quality of life among adults under the age of 65 with heart failure (56). Other studies have found that tangible-instrumental support and general social support are important as well in heart failure care, especially among women (57). Given the complexities of heart failure care, building the capacity of family caregivers to meet the informational and tangibleinstrumental support needs of a heart failure patient could reduce the psychological distress caused by the illness as well as improve its management among Pacific Islanders. Other studies among Native Hawaiians and Samoans have also highlighted the importance of educating and marshalling the support of family members in chronic disease management and the training of assertiveness skills for patients and family members to communicate more effectively with their healthcare providers (58,59).

Respite care for caregivers of people with heart failure was identified as a notable concern among participants who were caregivers, and strongly endorsed by participants with heart failure. We learned that for many Pacific Islander families caring for a person with heart failure, one family member was usually the primary caregiver, despite the presence of other capable adults in the home. Being the only caregiver placed considerable demands on that individual, who was solely responsible for tasks such as grocery shopping and cooking, dispensing of medication, and accompanying the ill family member to all medical appointments. The majority of the caregivers were also the primary source of financial support for the household and the parent of young children. In addition to managing these competing demands on their time, caregivers also felt that they lacked the knowledge (e.g., about causes and prognosis of heart failure) and training (e.g., about symptom and medication management) needed to care for a person with heart failure. Therefore, the primary caregivers also are in need of tangible-instrumental and informational support in caring for someone with heart failure.

A meta-analysis of 127 intervention studies targeting caregivers of people with dementia found that psycho-educational interventions that required active participation of caregivers had the broadest positive effects on caregivers' psychological well-being, knowledge and ability, and sense of burden (60). A review of community-based respite care found small to modest effects on caregivers' mental and physical well-being, but stronger effects on caregiver's satisfaction with respite (61). Exel, Graaf and Brouwer (62) identified three distinct groups of caregivers: caregivers who need and ask for respite, caregivers who need but will not ask for respite, and caregivers who have no need for respite. What distinguished the three groups of caregivers from each other was the strong sense of burden among the first two versus the perception of sufficient support by the third group of caregivers. The caregivers in our study appear to be characteristic of the first group of caregivers as they expressed a need for respite care, a strong sense of burden, and lack of support from other family members.

Interpersonal relations with healthcare providers were a notable barrier to heart failure care for Pacific Islanders. For example, Native Hawaiians and Samoans expressed concern about how their physicians communicated medical information to them and how they were treated by medical staff. A Samoan participant commented that the medical staff at her clinic often ridiculed her about her weight and size and that this is a common experience for many Samoan patients. A Native Hawaiian participant noted that his physician appeared too busy for his concerns and rushed him through the medical examination. Both Native Hawaiians and Samoans believed that they did not receive adequate explanations about their illness and medications' side-effects. Nevertheless, they also mentioned the need to be more assertive with their physicians regarding their medical care, and that being assertive in dealing with health providers is a problem for many Pacific Islanders. Studies have found that heart failure patients often report interpersonal conflicts with their healthcare providers including communication barriers, receiving inadequate medical information, and lack of trust in the physician's competence (63), all of which are associated with poorer treatment adherence (64).

Another notable barrier in the physician-patient relationship identified among Native Hawaiians was trust in the medical care provided by physicians. In contrast to Samoan participants, Native Hawaiians expressed a strong mistrust toward their physicians and Western-based medicine in general. This mistrust was evident in their preference for traditional Native Hawaiian healing practices over Western-based medicine in treating their heart failure and their reluctance in taking prescription medication. In some cases, Native Hawaiians mistrusted their physicians due to interpersonal reasons, such as the perception that their physician treated them like a "guinea pig" by not providing adequate medical information. Samoan participants, however, expressed a high degree of trust in their physicians because Samoan church officials advocated the use of physicians in treating many of their illnesses and thus they preferred Western medicine over traditional modes of healing.

Preferences for Western or traditional Hawaiian/Samoan medicine must be considered within the context of complementary and alternative medicine (CAM) use in the general population, as well as among the more specific population of chronic disease sufferers. Even in the general population, CAM use is prevalent. The use of CAM has steadily increased in the US, with 75% of adults reporting having ever used CAM (including prayer for health) (65). Prior studies have found that CAM use is associated with higher socioeconomic status, specific medical conditions including cancer and other chronic symptomatic illnesses, older ages, and female sex, among others (65-68). Thus, use of CAM among persons with chronic illnesses, regardless of ethnicity, is not unusual. However, the relationship between CAM use, health insurance, and health status is less clear. While one study concluded that CAM users report either good or very good health status (65), others have found the opposite to be true (67,68). Similarly, a 2006 study found that the highest percentage of people who had used any CAM did not have health insurance (65), whereas other studies did not find any relationship between insurance status and CAM use (68,69).

Among Samoans, preferences for Western versus traditional medicine may be disease specific. As several studies note, Samoans differentiate between *palagi* (Western illnesses) and *ma'i Samoa* (illnesses specific to Samoans) (58,69). The first category may be treated and cured through Western medicine; the second cannot and requires the intervention of a *fofo* or traditional healer (58). It was unclear whether Samoans in our focus groups regarded heart failure as *palagi* or *ma'i Samoa* but they did imply that anything pertaining to the heart should be treated by a Western physician. Another factor that may influence the preference for Western versus traditional Samoan care is the availability of traditional Samoan healers. No studies to date have included information regarding the availability of such healers, or issues relating to accessing a *fofo*, particularly in Hawaii.

Although Native Hawaiians expressed a preference for traditional Hawaiian healing over Western medicine, it is important to note that there is no evidence regarding whether Native Hawaiians are foregoing Western medical care in favor of traditional healers, or whether the two healing modalities are being used concurrently. Lack of insurance has been identified as a possible barrier to accessing Western medical care for Native Hawaiians (34). However, according to the Hawaii State Behavioral Risk Factor Surveillance System (BRFSS), 88% of Native Hawaiians reported having any kind of health care coverage, 73% had at least one person they regarded as their personal doctor, and only 9% felt that they had not received needed medical care because of cost within the past twelve months (6). As information about insurance status was not collected for this study, the extent to which lack of insurance may have influenced the preference for traditional Hawaiian healing practices versus Western medical care is unclear.

One explanation for the Native Hawaiians' strong mistrust of Western medicine may be related to their U.S. acculturation experience and socio-political relations with the U.S. Native Hawaiians are the indigenous people of Hawai'i whose islands were occupied and eventually acquired by the U.S. against the wishes of many Native Hawaiians (70). Therefore, there is strong mistrust among many Native Hawaiians toward the U.S. government and other Western-based institutions, including the medical profession (71). In contrast, Samoans voluntarily migrated to Hawai'i from both Samoa (an independent kingdom) and American Samoa (a territory of the U.S.) (72). These differences between Native Hawaiians and Samoans in their acculturation status and past political relationship with the U.S. may partially explain differences in attitude toward physicians who often reflect U.S. values and practices.

Native Hawaiians' reluctance in taking their prescribed heart failure medications (e.g., diuretics and beta blockers) is concerning given that such medications are necessary and effective in managing the life-threatening physical signs and symptoms (e.g., edema, dyspnea, increased heart rate) of heart failure. The reluctance of Native Hawaiians in taking such medication appears related to their past experiences with adverse side-effects of medications coupled with poor physician-patient communication regarding such side-effects and reasons for taking the medications. Therefore, any improvements in the communication between a physician and a Pacific Islander patient with heart failure could have a positive impact on heart failure care. Such improvements in communication might involve a detailed explanation of each prescribed medication to include its benefits and the possible side-effects; having a family member present to aid the patient in learning and understanding any information and instructions; having patients write down all medical directions or providing them with easy-to-read educational materials about their condition and medications; having the patient and/or the family member repeat back their understanding of any information or advice given by the physician; and having frequent follow-ups to assess for treatment adherence and any additional medical concerns.

Some methodological considerations are worth noting. A majority of the Native Hawaiian and Samoan participants were caregivers and thus the ideas and opinions expressed might be skewed toward their perspectives and experiences, and might not necessarily represent the perspectives of patients with heart failure. We are confident, however, that these perspectives were strongly represented, given that many of the participants with heart failure were elders in their communities. A prevalent and highly practiced Pacific Islander custom is to acknowledge and respect the presence of elders, and the younger caregivers demonstrated such respect in the focus groups. The low participation of people with heart failure could reflect the burden of this disease which made people too ill to leave their homes. Many of the caregivers did comment that their ill family member was not able to leave the home because of diminished physical functioning. It may be that the participants with heart failure who were physically able to attend the focus groups had less severe heart failure and/or better symptom management compared to those who were unable to attend the focus groups. This is speculation because we

did not collect any data from the participants regarding the severity of their heart failure or that of their loved ones. Therefore, the ideas and opinions of our eleven participants with heart failure may not fully represent all Native Hawaiians and Samoans with heart failure.

The other methodological consideration relates to the subjective nature of focus group data. A common methodological concern inherent in the use of qualitative methods is the high degree of subjectivity in the information collected and methods of data analysis. To minimize this effect in our study, we recruited from different Pacific Islander communities (e.g., urban and rural) in order to ensure that our participants reflected the larger Pacific Islander community. We also had reviewers of the transcripts extract themes and representative quotes independently, and negotiated differences among reviewers based on group consensus. Finally, it is important to note that qualitative methods are useful and necessary in developing culturally-informed interventions for managing chronic illnesses, especially for understudied ethnic populations.

#### 4.2. Conclusion

Our study supports the view that there are complex and possibly interrelated psychosocial, socio-cultural, and interpersonal factors affecting the recruitment, retention, and adherence of Pacific Islanders to a heart failure intervention. Subsumed by these factors are an avoidance-denial coping style and emotional distress (psychosocial), reliance on spirituality and religion as both a copying style and source of emotional support (socio-cultural), quality of physician-patient relations, and types of family support (interpersonal). From conversations with our participants and the findings of other studies, it is apparent that heart failure education plays a key role in treatment adherence. It is also apparent that acculturation factors (e.g., level of assimilation) may influence heart failure care among Pacific Islanders, although these effects may differ across specific Pacific Islander ethnic groups.

# 4.3. Practice Implications

To improve recruitment, retention and adherence among Pacific Islanders with heart failure, interventions targeting this population would be improved by 1) providing accurate and detailed information about heart failure and its treatment, 2) engaging the extended family in providing tangible-instrumental and informational support relevant to heart failure care, 3) promoting respite for the primary family caregiver, 4) including strategies to overcome financial barriers to obtaining necessary medications and healthy food options, 5) reinforcing an individual's spirituality and the church as sources of emotional support, and 6) providing tools to facilitate effective communication between physicians (e.g., listening skills) and patients (e.g., assertiveness skills). Heart failure interventions that also seek to address factors common to most empirically-supported health behavior change models, such as improving self-efficacy and fostering an internal locus of control within the context of a larger sociocultural system (e.g., socioeconomic status, acculturative stressors), are likely to be effective for Pacific Islanders.

Native Hawaiians' preference for traditional Hawaiian healing modalities may pose a challenge to ensuring that these patients are receiving necessary medical attention for their condition. This preference may reflect Native Hawaiians' mistrust toward Western medicine and/or a general trend toward the use of CAM among people with chronic diseases. For those Pacific Islanders with a preference for CAM, the building of good relationships with Western medical providers and encouraging these patients to share information about any CAM they are undergoing will be essential to improving treatment effectiveness. This approach could address the above considerations in two ways: 1) by increasing their trust of Western medical providers and 2) by encouraging a collaborative rather than an exclusionary approach to Western and CAM healing modalities.

#### Acknowledgements

We would like to extend our deepest gratitude to Puni Kekauoha, Adrianne Dillard, Uli'i Sati, and Merina Sapolu for their support of, and assistance, in this study. This study was supported by a research supplement grant to promote diversity in health-related research from the National Heart, Lung, and Blood Institute of the National Institutes of Health (Grant no. U01 HL079163).

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**Table 1** Participants' Characteristics from All Four Focus Groups

Characteristic	Participants with Heart Failure n = 11	Caregivers of a Person with Heart Failure n = 25	Combined Sample N= 36
Ethnicity			
Hawaiian	7 (64)	15 (63)	22 (61.1)
Samoan	3 (27)	7 (29)	10 (27.8)
Other	1 (9)	2(8)	4 (11.1)
Sex	` '	• •	, ,
Female	6 (55)	21 (84)	27 (75)
Male	5 (45)	4 (16)	9 (25)
Education level	` '	` '	• •
No high school diploma	1 (9.0)	2 (8.0)	3 (8.3)
High school diploma	5 (45.5)	10 (40.0)	15 (41.7)
College degree	3 (27.3)	11 (44.0)	14 (38.9)
Not reported	2 (18.2)	2 (8.0)	4 (11.1)
Marital Status	` '	, ,	, ,
Never married	0	5 (20)	5 (13.9)
Currently married	8 (72.7)	13 (52)	21 (58.3)
Disrupted marital status	2 (18.2)	5 (20)	7 (19.5)
Not reported	1 (9.1)	2 (8)	3 (8.3)
Age (mean years $\pm$ SD)	$65.9 \pm 13.2$	$50.5 \pm 13.2$	$55.3 \pm 14.9$

Data are n (%) or means  $\pm$  SD.

#### Table 2

Themes of heart failure beliefs, attitudes, and practices and their representative quotes extracted from 4 focus groups with Native Hawaiians and Samoans

#### **Domains and Themes**

# Representative quotes

#### **Heart Failure Beliefs and Attitudes**

- Avoidance and denial of illness
- Hopelessness and despair
- Religious/spiritual faith
- Trust in physician's care (high degree of trust among Samoans, low degree of trust among Hawaiians)

#### **Heart Failure Practices**

- Preference for physician's care (Samoans only) vs. traditional cultural healing practices (Hawaiians only)
- Prayers/faith in God
- Diet and exercise changes
- Stress management
- Subsistence lifestyle

- "I don't wanna go to the hospital...I don't want to hear [the diagnosis]."
- "[Heart failure] can hit you any time, and lot of us feel good and everything, we're in denial, like, I don't have that, I don't have that [heart failure]."
- "I wish there was a way so that you can take that burden cause it's constant...it's constant depression about not being whole again."
- "[God's] love will come through the doctors and the nurses....it's God's will, we accept what
- 'A doctor is usually the one that [Samoans] would all look up to."
- "I no really care for the doctor because...they hiding something from you....They don't come out with everything." (Hawaiian participant)
- "He was waiting and biding his time...[the illness] pretty much leaves him homebound". Patient:
- "Yeah, if it's something to do with the heart, they don't fool around [they see the doctor]." (Samoan participant)
- "My girlfriend says, don't take any pills, when the doctor says, oh, this is a new pill, try 'em...they're using you as a guinea pig. Whether that's true or not, I don't know, but I don't take any pills that my doctor gives to me. I don't go to that doctor."
- "I'm learning to eat vegetables. I'm learning to cut all the fat,..."
- ..we all know cut down on the salt, you know, exercise...'
- "Relieving stress and everything does help by calming down and doing some breathing techniques."
- "[Before] we'd catch the fish, we'd eat it and if there's too much we give to the neighbors, everything was fresh. But not anymore....take [Samoans] back to what they used to eat before...." Caregiver:
- "L $\bar{a}$  'au lapa 'au [Hawaiian medicinal herbs] is awesome...cause there 's no side effects, whatever 's
- [sic] wrong, it takes care of the body..."

   "There are times when you know, the doctors say, there isn't anything more that the doctors can do
- and so they pray [sic] and give it up to God's hands."

   "I think that maybe coming from the homestead side,...put the Hawaiians [sic] back on the land, and to grow their own food, so, subsistence...maybe we can start small by maybe having a class on growing Hawaiian food right in your back yard, and actually using that and putting it into your diet."

Note. The key themes presented here are summarized or aggregated concepts and phrases of participants' actual responses and the representative quotes are listed by type of participant - heart failure patient and caregiver.

#### Table 3

Themes of heart failure social support and barriers to heart failure care and their representative quotes extracted from 4 focus groups with Native Hawaiians and Samoans

#### **Domains and Themes**

# Representative quotes

### **Heart Failure Social Support**

Informational supports

- · Family's knowledge of illness and medications
- Training of caregivers Tangible-Instrumental support
- Family offering and sharing in care giving responsibility
- Respite for caregivers in the family

## **Barriers to Heart Failure Management**

- Lack of heart failure knowledge
- Poor doctor-patient communication
- Lack of trust for physicians (Hawaiians only)
- Financial burdens
- Making needed diet changes
- Competing demands on time

- "I was a little bit afraid of everything but then my kids and the husband was so helpful so...educate your own family about [heart failure]...cause they know what's going on and help me with the food, with the exercise...I think its better."
- [We] need somebody to help explain the medical jargon and...what's happening in the body."
- "We need to have our kids involved too. Like my daughter...I took her [to the] doctor with me and she never thought that I had all these problems.... Today, she treating me.'
- "[Heart failure care] gotta have cooperation, [from] the family, yeah."
- "So, the caretaker needs a lot of support from the person they taking care of."
- "My experience with my sister was I didn't know what heart failure was

### Patient:

- "I think most Hawaiians no understand what the causes are [for] heart failure..."
- "I would really love...education, education, like for all of us around here we do not know the difference between heart attack and heart failure."
- "You don't just sit across a desk and say well, how is the heart today? You have to look them in the eye when you're talking to 'em. And you have to appear to them to be very interested.'
- "I no really care for the doctor because you ask them something, they hiding something from you. They don't come out with everything.... I said, what's this drug for? He [the doctor] said this is the best drug for you, he never answer my question."
- "One of the challenges is money."
- "Samoan's [sic] love to eat the fat."

Caregiver:

• "Time is always an issue and uh, you know family responsibilities like you get kids."

Note. The key themes presented here are summarized or aggregated concepts and phrases of participants' actual responses and the representative quotes are listed by type of participant - heart failure patient and caregiver.