



Understanding disparities in clinical trials for Native Hawaiian men

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Abstract

Understanding low rates of participation by minority populations in clinical trials is critical for reducing and eliminating disparities. We examined beliefs and attitudes of Native Hawaiian men related to illness and cancer to better understand their rates of participation in clinical trials. We conducted face-to-face interviews with Native Hawaiian key informants throughout the State of Hawai'i using quota sampling methods to obtain a range of perspectives about attitudes towards health care seeking to provide insight into low clinical trials participation. Interviews were audio-taped, transcribed, and independently coded by researchers. Thematic analysis guided the extraction of relevant data from the discussions. Key informants (N=16) suggested the following beliefs and attitudes regarding clinical trials participation: 1) mistrust in the healthcare system, 2) external locus of control, 3) gender norms, and 4) the customary pono (righteousness, to make right) practice towards family/community to model and maintain good health, including participation in cancer clinical trials. Native Hawaiian men in this study expressed hesitation in the benefits of formalized health care. Many men described experiences of racism, inequity, and injustice associated their interactions with health care providers. These encounters were factors that influenced their healthcare practices and beliefs towards maintaining health and longevity.

Keywords

Native Hawaiians; cancer; clinical trials; gender norms; disparities; distrust

Cover Page Footnote

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ABSTRACT

Understanding low rates of participation by minority populations in clinical trials is critical for reducing and eliminating disparities. We examined beliefs and attitudes of Native Hawaiian men related to illness and cancer to better understand their rates of participation in clinical trials. We conducted face-to-face interviews with Native Hawaiian key informants throughout the State of Hawai‘i using quota sampling methods to obtain a range of perspectives about attitudes towards health care seeking to provide insight into low clinical trials participation. Interviews were audio-taped, transcribed, and independently coded by researchers. Thematic analysis guided the extraction of relevant data from the discussions. Key informants (N=16) suggested the following beliefs and attitudes regarding clinical trials participation: 1) mistrust in the healthcare system, 2) external locus of control, 3) gender norms, and 4) the customary *pono* (righteousness, to make right) practice towards family/community to model and maintain good health, including participation in cancer clinical trials. Native Hawaiian men in this study expressed hesitation in the benefits of formalized health care. Many men described experiences of racism, inequity, and injustice associated their interactions with health care providers. These encounters were factors that influenced their healthcare practices and beliefs towards maintaining health and longevity.

Keywords: Native Hawaiians; cancer; clinical trials; gender norms; disparities; distrust

INTRODUCTION

Although the testing of novel cancer therapies can lead to breakthroughs in life-changing cancer treatments, the overall low participation rates in cancer clinical trials nationwide have been a consistent challenge for researchers to overcome. It is estimated that only about 8% of eligible cancer patients ultimately enroll in clinical trials (ACS CAN, 2018). Additionally, the

low representation of minorities in clinical trials reduces the generalizability of the cancer treatment findings (Murthy et al., 2004). There is inconclusive data on recruitment outcomes of minorities and Caucasian participants into clinical trials (Hirano et al., 2012; Chen et al., 2014). Efforts to increase minority participation by the National Institutes of Health (NIH) has found that the inclusion and reporting of minority enrollment in NIH-funded randomized controlled trials have not improved over the years (Geller et al., 2008).

Low clinical trial participation rates exacerbate mortality disparities among minority groups (Chen et al., 2014). Pacific Islanders, including Native Hawaiians, are among the most understudied populations in the US when it comes to medical research (Gollin et al., 2005). Nationally, Asian/Pacific Islander (API) enrollment in cancer clinical trials is comparable to other groups, except for lower enrollment in lung and colorectal cancer trials compared with Caucasians (Murthy et al., 2004). However, this broad category of API does not adequately reflect enrollment by Native Hawaiians who only represent 2.7% of this racial group, and less than half of those who identify as Native Hawaiian reside in the State of Hawai'i (US Census, 2018). With the low participation of cancer patients in clinical trials and the growing ethnic minority population in the US, it is essential to include these groups in trials to accurately reflect the US cancer population.

Native Hawaiians make up about 42% of the Pacific Islander population in the US. The Pacific Islander population overall has increased more than three times faster than other US population (Hixson et al., 2012). Based on data from 2012-2016, an average of 7,011 Hawai'i residents were diagnosed with cancer each year, with breast and prostate cancer being the most commonly diagnosed cancers in Hawai'i (Hawai'i Tumor Registry, 2020). Among Hawai'i's largest ethnic groups (i.e., Caucasian, Chinese, Filipino, Japanese, and Native Hawaiian), the age-adjusted rate per 100,000 for breast cancer mortality for females was 19.9 for Caucasian, 12.2 for Japanese, 11.3 for Filipino, and 9.9 for Chinese. During this same time period, Native Hawaiian women had the highest mortality (29.2 per 100,000) from breast cancer compared to Hawai'i's other largest ethnic groups. For prostate cancer, the age-adjusted mortality rate per 100,000 was 18.7 for Caucasian, 15.1 for Filipino, 9.1 for Japanese, and 5.0 for Chinese. Native Hawaiian men had the highest mortality (23.1 per 100,000) from prostate cancer compared to Hawai'i's other large ethnic groups. Factors that contribute to higher mortality rates from cancer among Native Hawaiians include diagnosis at a later stage, high prevalence of behavioral risk factors, and genetic markers of tumor aggressiveness (Mokuau et al., 2008).

A study conducted by Bantum and colleagues (2015) looking at the representation of ethnic groups in 178 cancer treatment trials in Hawai'i, conducted between 1992 and 2004, found that Native Hawaiians had the lowest clinical trial participation among Hawai'i's other major ethnic groups for both men (8.7%) and women (13.3%). Enrollment of Native Hawaiian women in cancer treatment trials was 13.3% compared to 62.9% for Asian Americans and 22.3% for Caucasian women. Similarly, 8.7% of Native Hawaiian men enrolled in these trials compared to 58.7% for Asian Americans and 30.1% for Caucasian men. This study highlights the gender disparities, with significantly higher participation of Native Hawaiian women than Native Hawaiian men in treatment trials.

Since 1993, the University of Hawai'i Minority Based Community Clinical Oncology Program (UH-NCORP) has worked to improve statewide minority accruals to increase equity in participation and support clinical trials to provide better outcomes than existing standard of care

for all ethnic groups in Hawai‘i. In 2010, the Hawai‘i Cancer Consortium (HCC) was established through the University of Hawai‘i Cancer Center (UHCC) to promote cancer research in Hawai‘i through the state’s major medical institutions and physicians in private practice. This consortium allowed clinical trial sponsors to work with HCC/UHCC as a single point of contact for all administrative functions related to clinical trials. It streamlined the coordination of trials between patients and the health care providers in medical institutions.

In 2005, as part of an initiative of the National Cancer Institute (NCI) to inform the public nationally about clinical trials, the UH-NCORP began statewide efforts to improve accruals to trials through the establishment of a Clinical Trials Education Coalition (CTEC). The purpose of CTEC was to bring together local cancer control stakeholders to promote participation in clinical trials among cancer patients using a variety of strategies. For example, one strategy was for UH-NCORP staff to conduct a review of the medical charts of newly diagnosed patients at HCC facilities to identify eligible patients. The UHCC also conducted a series of media campaigns between 2002 – 2009 (e.g., print articles, press releases through radio, newspapers, and local television channels) to raise awareness of clinical trials within Hawai‘i’s population. However, these efforts were limited and not tailored to Native Hawaiians. UH-NCORP and the Native Hawaiian Healthcare System trained lay Native Hawaiian patient navigators to become conversant in methods for referring patients to clinical trials. Some of these referral efforts likely supported trial accrual improvements and an overall congruence in accruals across patients by ethnicity. However, a recent analysis of clinical trials accrual data identified a disparity in trial accruals among Native Hawaiian men in cancer prevention trials that we sought to better understand (Bantum, 2015).

Previously, a range of studies have been conducted to better understand and improve the participation of Native Hawaiians in clinical trials. These studies have looked at health literacy, levels in clinical trial recruitment materials (Harrigan et al., 2014), identified primary care physicians’ barriers to referring Native Hawaiian patients to trials (Ka‘ano‘i et al., 2004), explored oncologists knowledge of clinical trials participation by Native Hawaiians (Ka‘ano‘i et al., 2002), and the need to include the Native Hawaiian community’s perspective and conduct community education about clinical trials (Fong et al., 2003).

A study of Hawaiian/Pacific Islanders and Filipino participation in clinical trials found that Native Hawaiians/Pacific Islanders were more reluctant and fearful of participating in clinical trials compared to Filipinos (Gollin et al., 2005). This study cited the lack of trust and confidence in outside investigators, lack of adequate information about the purpose of the research, and concerns that the research would not benefit their community as the main barriers to medical research participation. The Native Hawaiian community’s apprehension of clinical trials has been well documented (Gollin et al., 2005, Townsend et al., 2015).

In Hawai‘i, Native Hawaiians bear disproportionately higher rates of chronic illnesses including obesity, diabetes, cardiovascular diseases, and cancer compared to the overall state population (Look et al., 2013). Disparities in social and economic factors including isolation, lower income, lower rates of home ownership, and lower educational attainment may have increased high-risk health behaviors among Native Hawaiians (Blaisdell, 1989; Galinsky et al., 2017; Look et al., 2013).

Poor health outcomes are particularly more apparent in Native Hawaiian men (kāne) who are less likely than Native Hawaiian women to adopt preventive health services (Hughes, 2004).

To better understand current beliefs and attitudes of Native Hawaiians, specifically Native Hawaiian men, towards decision-making about health care and clinical trials, we conducted interviews with Native Hawaiian key informant representatives and community members from several Native Hawaiian communities on the islands of Maui, Moloka‘i, and O‘ahu.

METHODS

This research was conducted in the State of Hawai‘i in 2015-2016. Qualitative interviewing methods were used to collect study data. Our study utilized a purposive sampling frame called maximum variation sampling, which is often used in qualitative inquiry (Patton, 2002). We purposively selected a demographically heterogeneous set of participants based on their perceived ability to provide information-rich, illuminative in-depth data concerning the attitudes towards illness, health-seeking information, and cancer in Native Hawaiian men. Our goal was to capture the breadth and depth of differing perspectives to better understand low clinical trial participation among Native Hawaiian men. Interviews were conducted using standardized semi-structured, open-ended questions from an interview guide and lasted between 45 minutes to 1 hour (Table 1). Our interview guide is based on previous work to document the cancer-relevant knowledge, attitudes, behaviors, and information-seeking practices of Pacific Islanders in Hawai‘i (Cassel et al., 2020).

Table 1. Key Informants discussion guide

All participants
If you or someone in your family does not feel well, like has shortness of breath, feels dizzy, has a lump that does not go away, what would you do?
Do family members, family friends, or people you care about give you health advice?
Who do you trust for medical information? If you wanted to learn about cancer, who would you trust to give you information?
Who do you trust for medical advice? If you had cancer and needed advice about treatment, who would you trust to give you advice?
What do you think when you hear the word cancer?
If you found out that you or someone in your family was diagnosed with cancer and needed treatment, what do you think is the best thing to do?
ONLY ask if participant had cancer
How did you find out about clinical trials?
Did you have concerns about joining a trial?
What helped you decide to join a clinical trial?

Interviewers were members of the research team who were either members of the Native Hawaiian community or who had extensive research experience working within the Native Hawaiian community. We used a set of interviewers to conduct the study, one who was a Native Hawaiian male, one who was a Native Hawaiian female, one male, and female who were not Native Hawaiians but who were intimately familiar with Hawaiian culture. Interviewers were trained to describe clinical trials and answer questions before the start of the interviews. In conducting the interviews, it was important to discuss this cultural or gender discordance with

the interviewees to address any potential issues that may have surfaced. Acknowledgment of the etic (outsider) or emic (insider) perspectives of the interviewers served to prevent reactivity to sensitive interview questions linked to Native Hawaiian cultural and gender norms. The study design, protocols, and materials were reviewed, and approved by the University of Hawai'i Institutional Review Board (IRB) and Papa Ola Lōkahi IRB, a Native Hawaiian health board. All participants were provided with IRB-approved copies of the study documents that included a study overview, a brief demographic survey, and the study consent forms in English. Only participants who provided written consent were interviewed. Participants were given a \$20 gift certificate for their participation.

Recruitment and Sample

In identifying potential participants for interviews, a purposive maximum variation sampling framework was used to obtain perspectives from distinct members of the Native Hawaiian community. Participants were personally recruited by the researchers through their affiliations with organizations serving the Native Hawaiian community and their leaders. These organizations included the Native Hawaiian Healthcare System, Papa Ola Lōkahi, and the Native Hawaiian homesteads including Kula No Na Po'e Hawai'i o Papakōlea, Kewalo, Kalāwahine communities.

Purposive sampling, also known as judgmental, selective, or subjective sampling, is a form of non-probability sampling in which researchers rely on their judgment when choosing members of the population to participate in their study. We chose to interview: 1) people who were known leaders of the Native Hawaiian community, either through their positional or occupational influence; with the thought that these key informants could speak to some potential patterns within the broader Native Hawaiian community, and 2) people who did not have obvious leadership roles so that they could speak more directly to their own personal experience regarding cancer, cancer research, and entry into cancer clinical trials thereby providing a more typical case perspective. Saturation was achieved when we identified redundancy in themes among new interviewees. A total of twenty-eight Native Hawaiians were asked to participate and sixteen agreed. The most common reason for declining participation was due to the inconvenient timing of the planned interviews. A list of questions was created to better understand their response to illness, obtaining health advice, knowledge of cancer, seeking cancer treatment, and clinical trials (Table1).

Data Analyses

All participant interviews were conducted by three of the co-authors (MT, KC, and GL) and a research assistant on the study. The interviews were audio-recorded and transcribed verbatim by study staff. Transcriptions of these interviews were reviewed and coded by members of the research team. Analysis of interview data followed an inductive approach, with the four coders independently examining the transcribed interview text and creating a descriptive summation of each participant's responses or codes. Patterns found in the initially coded data were then combined and organized into concepts or themes that captured the essence of the participants' responses. All coders then met on two separate occasions to suggest themes that were commonly noted during the independent analysis. After all transcripts were analyzed, there was a conversation about whether any additional themes were present in the data. Once all four coders agreed to thematic saturation (i.e., no additional themes were able to be generated from

across the distinct interviews), coders proceeded by assigning the quotes most relevant to each designated theme.

RESULTS

Demographics

Sixteen participants engaged in the key-informant interviews (Table 2). This included 12 males and 4 females. Males were intentionally included at a higher rate because the study focused on understanding why male participation rates were low. Four of the participants were cancer survivors (two males and two females). Both male participants had been diagnosed with prostate cancer, and one female participant had breast cancer, while the other had colon cancer. There was a large age range (26 – 74 years), and participants had a mean age of 50 years (± 16.3 SD). The majority (68.8%) of the participants were either married (43.8%) or in a long-term partnership (25.0%). All participants identified as Native Hawaiian; however, most also identified with multiple ethnicity labels (Native Hawaiian, Asian, and Caucasian = 6; Native Hawaiian and Caucasian = 4; Native Hawaiian and Asian = 2), while only four participants identified Native Hawaiian as their sole ethnic group. Two participants currently live on the island of Moloka'i, two participants reside on Maui, and the remaining 12 live on O'ahu. Two participants lived on the continental USA for a period of time (4 years for one and 12 years for another), and all participants were born in Hawai'i.

Table 2. Demographics of Native Hawaiians ($n = 16$) interviewed in this study.

Residence	N (%)	Education	N (%)
O‘ahu	12 (75%)	High School	3 (19%)
Moloka‘i	2 (12.5%)	Trade School	1 (6.3%)
Maui	2 (12.5%)	Some College	3 (19%)
		College	5 (31%)
		Adv. College degree	4 (25%)
Gender		Household Income	
Male	12 (75%)	< 25K	2 (12.5%)
Female	4 (25%)	25-40K	1 (6.3%)
		40-70K	1 (6.3%)
		>70K	10 (62%)
		Missing data	2 (12.5%)
Marital Status		Employment	
Married	7 (44%)	Full Time	9 (56%)
Divorced	3 (19%)	Part-time	2 (12.5%)
Long Term Partner	4 (25%)	Self-employed	1 (6.3%)
Single	2 (12.5%)	Retired	2 (12.5%)
		Student	1 (6.3%)
		Out of work > 1 year	1 (6.3%)
Household Size		Household with Children	
2 persons	5 (31%)	0 children	5 (31%)
3 persons	2 (12.5%)	1 child	4 (25%)
4 persons	6 (38%)	2 children	4 (25%)
5 persons	2 (12.5%)	3 children	2 (12.5%)
7 persons	1 (6.3%)	Missing data	1 (6.3%)

The following four themes emerged from our interviews with key informants: 1) mistrust of the healthcare system (56.3%); 2) external locus of control (62.5%); 3) gender norms (62.5%); and 4) *pono* practices, (62.5%).

Qualitative Findings

Mistrust of the Healthcare System (56.3%). Half of the participants stated that mistrust of the healthcare system was a primary barrier for Native Hawaiians to participate in clinical trials. The belief that doctors were not interested in their health or well-being led to their concern that if they were ever recommended a clinical trial (where there is no certainty that the novel treatment would work), they would not enroll because of their lack of trust in their physician and/or researcher to provide them with the best available care, and also not wanting to be seen as a “guinea pig” or trial subject. Some participants also talked about hospitals being a difficult place to navigate, and of having to see too many ‘people’ before getting medical care and that they just give up. Male participants also reported ignoring symptoms. When they do seek medical care, it

is because they are hurting and often it is too late, and thus there is the perception that hospitals are places where one goes to die.

Some male participants talked about the lack of medical services for men in the area where they lived as a reason for not seeking help, and there is also a fear of doctors and hospitals. For one participant, cancer treatment meant pain, suffering, and a decrease in quality of life as he observed relatives go through cancer treatment.

Some representative quotes include:

I trust you, I trust people I know. I don't really trust the system. They don't want us to get better. They just want to make it hard to get care. (M1)

I don't really think they really care if I get better. I think they would prefer I wasn't using their services. I think they would prefer I wasn't alive. So, if they offer me something that they are not sure if it's going to make me better, it doesn't really make me want to try it out for them. (M1)

I think there's a lack of people feeling comfortable with their providers, and they go, and they don't feel like they're being heard or listened to. (F1)

External Locus of Control (62.5%). External locus of control refers to the extent to which individuals believe that they cannot control events and outcomes in their lives. Over half (56%) of Native Hawaiian men expressed the belief that they could likely die young - like their parents, and they felt powerless to change that.

The idea of not living past a certain age and not having control over their health appear to be common among Native Hawaiian men, and because of this belief, they often have a strong desire to live precariously without much regard for their health or safety. One participant related that almost all the women in his family, except his mother, had been diagnosed with cancer. It should be noted that one participant suggested that older Native Hawaiian men were more likely than younger Native Hawaiian men to feel they had no control over their health or longevity.

Native Hawaiian men also expressed feeling demoralized. One participant stated, "There's not a lot to live for." Participants felt that once they had taken care of their families, their responsibilities were over, and they ceased to have a purpose. Upstream historical and social determinants for this perspective are important to consider. Native Hawaiians and other displaced indigenous people experience historical trauma that influences their worldviews. Regarding illness, the point of view often expressed is that if they were diagnosed with a fatal disease like cancer, they did not want to be treated and seen as an experiment. Cancer is widely viewed as a death sentence, a disease that cannot be cured, and one they have no control over. One participant asked: If cancer treatment will not help, why go through treatment? Another participant explained that Native Hawaiian men would stay away from treatment if they thought the treatment was worse than death itself.

Some representative quotes include:

The big scare for me right now is I am not going to be around, my son is not going to have me because my dad died when he was about 55 and that means that I have about 10 years left for me, and all my uncles died early. I got one uncle. He kind'a still hanging in there but men in my family die young. They don't get old. So, I kind'a have that in my

mind like I was just going to die young, (it) was going to be me so I used to live with that mentality. I used to live hard. (M2)

(Native Hawaiian men) do not think they are going to live past a certain age. (M3)

My grandfather did not seek (cancer) treatment. I think he accepted his fate. In his mind he was thinking he's old already...so what is the point? (M4)

(learning about clinical trials) ...in our communities there is a genuine sense of why bother...there is no point. (M3)

Gender Norms (62.5%). Gender norms refer to the range of behaviors that are considered acceptable based on gender. About 56% of Native Hawaiian men believe that being sick somehow lessens them in the eyes of their families, therefore, they do not seek help when they need it because they anticipate they will not be seen as the men they are supposed to be. The idea that the Native Hawaiian man is strong is pervasive. For many, their fathers were their role model – men who lived by fishing and hunting but who died young. Participants explained that their fathers never took care of their health because they believed that they were strong and could heal themselves, and furthermore, they never talked about their health. Within this theme, there were many instances in which men suggested that they did not know if they would continue to be of value to their family if they became sick.

Being Native Hawaiian is a source of great pride, but it also implies the economic reality facing Hawaiian men, which suggests limited opportunities to achieve economic stability and security. There is a reckoning that if their situation were different (e.g., they had access to their traditional lands) they would have greater economic opportunities. Through colonization and westernization, Native Hawaiians have been forced from their traditional lifestyle. Because of this dramatic change in lifestyle and environment, Native Hawaiians are challenged to survive in today's economy. Male participants explained that men are expected to be the breadwinner, and if they are not able to fulfill this role, it has them feeling as not living up to their family's expectations.

Some representative quotes include:

(men) they don't seek help because either they are proud...like if they come up with some disease, it lessens them, so they are not the man they are supposed to be. A man with diabetes is different than a man with no diabetes...they chase the disease instead of preventing the disease from happening. (M5)

(men) ignore (symptoms) or whatever...men are just like that...ah, I will be fine, no worries. But it is not fine and it's kind of like a pride thing that they don't want to admit to being sick. They don't want to get help. (M6)

I do believe there is fear of, by acknowledging those weak spots, like vulnerability is within themselves, I think that perception is that it will decrease their sense of manliness and strength. (F2)

In the past, it would be that men were key in providing for the family, but it is because they are going to protect the children and the women for the future. So, sort of rebalancing how you look at that social structure actually, it's the children who are most important, and then the women and then the men. (F2)

Because the man is the dominant figure in the community and in his house, so any sign of weakness is like a failure. (M7)

Pono (62.5%). Many participants also expressed a desire to do what is right (*pono*) by taking care of their health, but they also felt that by being *pono* it would take them away from friends and things they liked to do, which meant an unhealthy lifestyle. They also expressed difficulty finding support to help them engage in a healthy lifestyle. There is no direct translation of the word *pono* in English. It is usually translated to mean righteous or proper, but the word has a much broader meaning and can also be defined to signify moral qualities, correct or proper procedures, duty, moral fitting, should, ought, must, necessary and so on (Bashman, 2008). Among our key informants, there was a sense that by being *pono* they were being a good Hawaiian, and a strong Hawaiian man would participate in clinical trials as a matter of pride and duty.

Some participants recognized the value of being *pono*, by demonstrating good health habits like getting regular cancer screenings, their children would model their health behaviors.

Some representative quotes include:

There are times that I don't feel like dealing with the junk stuff that I have done, but at the end of the day if I want to be pono with myself I have to own up to that...and I think that if more people at least try to be more pono, then that would make a difference. (F2)

If you are not coming (to screening) for you, come for your kids. Just come in for your kids because you want to be with them. As soon as possible, because they look at you first as a mentoring person that teaches them. So, if you teach them good things by coming to screenings and stuff like that, then they will pick up on that. (M6)

DISCUSSION

Our interview findings elucidate the complex nature of considerations relevant to Native Hawaiians, particularly males, in caring for their well-being and health. While there are many views not captured in our interviews, we did find several consistent themes that were ultimately included in our findings. Strong mistrust in health care is well documented. A study on heart failure treatment among Native Hawaiians (Kaholokula et al., 2008) found that Native Hawaiians expressed strong distrust toward their physicians for reasons including feeling like a “guinea pig,” of not being provided with enough medical information, and their preference for traditional Hawaiian healing methods. A few participants in our study expressed their preference for *lā'au lapa'au* (traditional Hawaiian medicine) instances where they sought advice from their *lā'au lapa'au 'ōlohe* (Hawaiian martial arts teacher who may also be a healer). As one participant explained when asked about who do you trust for medical advice: “Depending on the illness, nine times out of ten, I will talk to my *lā'au lapa'au 'ōlohe*.”

A study about preferences for informed consent to research stored biological specimens (Fong et al., 2004), found that Native Hawaiians (78%) were more likely than Caucasians to want a detailed informed consent process. Distrust of Western or allopathic medicine likely stems from the historical experience of Native Hawaiians under colonization by the United States (Santos, 2008). Research suggests that the historical trauma Native Hawaiians experienced affects later generations even more acutely, by continuing to feel subdued to the

colonizing power (Pokhrel & Herzog, 2014). Historically, Native Hawaiians have been subjected to abuses and racism along with the loss of land and power that has led to internalized racism (Fong et al., 2003, Kaholokula et al., 2008), and has eroded their trust in Western medicine. However, mistrust can also be attributed to uncertainties about insurance coverage or lack of access to insurance. A participant explained that patients could be turned away because not enough doctors are available, or because they lacked the appropriate health insurance, e.g., not all doctors accept Medicaid or Quest. Limited awareness of the purposes and benefits of clinical trials also seem to be prevalent. A participant summed it up as follow: *“I think basically most of us don’t even know that (clinical trials) it is there...most Hawaiian men don’t even bother...you know what I mean...if they don’t hear about it, they don’t know about it.”* Ultimately, it may be that clinical trials have not been promoted in a culturally sensitive way, as one participant suggested. There have been several culturally adapted novel health promotion interventions (PILI ‘Ohana and KāHOLO projects) targeting Native Hawaiians to address health disparities in obesity, diabetes, and cardiovascular diseases that have resulted in positive and promising outcomes that may be used to promote trials (Kaholokula et al., 2018).

Several other points were made during the interviews that, while less frequent, were extremely informative. Three-quarters of study-participants reside on O‘ahu (island). Another 12.5% reside on Moloka‘i, which has a smaller (7,000) and more rural population, comprised of a larger proportion of Native Hawaiians compared to O‘ahu (~950,000). Clinical trials are not available on Moloka‘i or Maui, thus, prospective participants must fly to O‘ahu for treatments, which undoubtedly impacts their knowledge and view of trials. The reasons for the lack of availability of clinical trials include: the small populations in neighbor islands, the challenging cost of offering comprehensive health services; the lack of specialty doctors (including oncologists), long distances to health care facilities, and higher costs of everything. However, Hawai‘i’s neighbor-island populations provide potential opportunities for increasing knowledge and developing clinical trials for neighbor-island patients residing off O‘ahu.

The following quote presents one of the reasons for not wanting to leave one’s home for treatment or for accessing clinical trials that makes it even more imperative: *“When you are connected to a place, you want to die in that place. You don’t want to leave home and go die in a place that is strictly for treatment, that’s the fearfulness.”*

Including family-members in the decision-making aspects of clinical trial participation was mentioned by several participants as important to whether they would ultimately opt to participate, or not. Family perception of whether clinical trials would be beneficial, and their understanding of the clinical trial, were seen as large motivators for inclusion. Some Native Hawaiian families continue a traditional healing practice known as *ho‘oponopono*, which is used to resolve conflict and bring the family to a consensus on issues facing the family and community. *Ho‘oponopono* is a process of healthy interaction, which is also applied to the medical arena (Ka‘opua, 2003). In the case of medical treatment, family members can gather, prior to medical treatment, to address the illness through a spiritually-grounded family discussion session to enhance adjustment and adaption to disease (Ka‘opua, 2003). *Ho‘oponopono* may entail pooling of the family’s emotional and spiritual resources, and in the case of medical care, potentially assigning individual responsibilities to address the disease, to better understand the meaning of the illness to each family member and to the community. The process of *ho‘oponopono* can reduce the negative implications of disease as a family issue.

In a focus group study to improve breast cancer screening among Native Hawaiian women (Ka'opua, 2008), participants suggested that screening be framed as a commitment to family well-being involving emotional support from family members. In a study by Mokuau and colleagues (2008) on the feasibility of a family-oriented intervention for Native Hawaiian women, all participants appreciated the incorporation of Hawaiian cultural values in the study, that increased their level of comfort and increased likelihood to refer others to the study. Incorporating *ho'oponopono* and other Hawaiian values into treatment and interventions could provide an avenue to further build connections between Western medicine and Native Hawaiian populations and successfully increase clinical trial participation (Look et al., 2013). It should be noted that participation in clinical trials by Native Hawaiian males has improved. Their participation into clinical trials is now 12.1% (OnCORE/CTMS) compared to earlier data of 8.7% participation (Bantum, 2015). The participation of Native Hawaiian women has also improved to 15.7% from 13.3%. We have seen an increase in treatment, symptom and cancer delivery trials and we are encouraged by these improvements. It is important to sustain this increase in clinical trials because Native Hawaiian outcomes for certain cancer types can be improved, and additional work needs to be done to decrease these disparities.

A few aspects of this project could be deemed as limitations. It is important to note that the sample size is small. The Native Hawaiian women in the study were interviewed for their perspectives on health-seeking attitudes of Native Hawaiian men, clinical trials, and Native Hawaiian cancer survivors; however, their collective responses are not representative of all Hawaiian women or men. Additionally, we did not sample according to age, and the views of older Native Hawaiian men may not be representative of younger Native Hawaiian men. Moreover, there are many differences within any one island, and those differences (i.e., distance to clinics and treatment facilities, employment, socioeconomic status, and ethnic diversity) could greatly impact the findings. Originally, we sought to interview key informants, with the thought that they would have gathered sentiments from the community. After engaging in those interviews, we decided to extend the perspective to include more singular viewpoints of community members. There were no remarkable differences in responses between key informants and community members.

It is customary to share the findings with study participants and seek their consensus; however, since we interviewed participants individually and in different locations, it would have been challenging to carry it out in a timely and efficient manner; therefore, we consulted with the University of Hawai'i Cancer Center's Native Hawaiian Community Advisory Board that acted as a proxy and provided feedback and suggestions on study findings from a Native Hawaiian perspective

CONCLUSION

Despite the challenges presented by our current study in assessing factors contributing to clinical trial accruals for Native Hawaiian men, we have identified areas for further research that may help improve the reach and inclusiveness by: a) exploring ways of improving access to clinical trials for providers with cancer patients on the neighbor islands, b) building trust between Native Hawaiians and their health care providers and oncologists, through cultural competency training, and c) identifying role models or cancer survivors in the Native Hawaiian community who can champion clinical trials. It is imperative for current investigators to understand and

accept responsibility for the deficiencies and injustices caused by prior research and to now work together with Native Hawaiian community members to build trust.

A strategy that may support our future work is the use of community-based health-activated support groups. Recent research by Cassel (2020) has demonstrated in the area of colon cancer screening that the use of community-based health-activated support groups may help Native Hawaiian men to adopt healthy behaviors. The use of the health activated support groups may also be used to introduce and promote cancer clinical trial research to Native Hawaiian men.

National recommendations for facilitating research in ethnic minorities in a more respectful and inclusive way include making the informed consent process a more collaborative and continuous process (Corrigan, 2003), as well as national and local efforts to partner with community organizations in order to include partners who can speak to the validity of the research (Skaff et al., 2002, Fong et al., 2003, Parra-Medina et al., 2004, Davis et al., 2009). Research shows that studies benefit when a partnership based on trust and respect between the investigators and community is established (Fouad et al., 2000).

Future studies should aim to better understand the barriers to health care, build trust, and identify role models of healthy behaviors for Native Hawaiian men, in a culturally sensitive way, with the hope of developing more equitable health and cancer care for Native Hawaiians. These studies should also more fully identify the strengths within the Native Hawaiian community and how those strengths can be incorporated into health promotion.

REFERENCES

- American Cancer Society Cancer Action Network (ACS CAN) (2018). *Barriers to patient enrollment in therapeutic clinical trials for cancer – A Landscape Report*. Washington, DC.
- Bantum, E.O., Cheng, I., Cassel, K., Kaopua, L.S., & Yamato, R. (2015). Cancer clinical trials in Hawai 'i: Who's being represented. *Journal of Clinical Trials*, 5(213), 2167-0870. <https://doi.org/10.4172/2167-0870.1000213>
- Bashman, L. (2008). Mele Lahui: The importance of Pono in Hawaiian Poetry. *Te Kahararoa* 1:152-164.
- Blaisdell, K. (1989). Historical and cultural aspects of Native Hawaiian health. *Social Process in Hawai'i*, 32(1), 1-21.
- Cassel, K., Lee, H.R., Somera, L.P., Badowski, G., & Hagiwara, M.K.I. (2020). Cultural considerations for conducting the health information National Trends Survey with Micronesian communities: Lessons from a qualitative study. *Hawai'i Journal of Health & Social Welfare*, 79(6 Suppl 2), 64.
- Cassel, K.D., Hughes, C., Higuchi, P., Lee, P., Fagan, P., Lono, J., Ho, R., Wong, N., Brady, K., & Ahuna, W. (2020). No Ke Ola Pono o Nā Kāne: A culturally grounded approach to promote health improvement in Native Hawaiian Men. *American Journal of Men's Health*, 14(1), <https://doi.org/10.1177/1557988319893886>
- Chen Jr, M.S., Lara, P.N., Dang, J.H., Paterniti, D.A., & Kelly, K. (2014). Twenty years post-NIH Revitalization Act: enhancing minority participation in clinical trials (EMPaCT): laying the groundwork for improving minority clinical trial accrual: renewing the case for enhancing minority participation in cancer clinical trials. *Cancer*, 120, 1091-1096, <https://doi.org/10.1002/cncr.28575>

- Corrigan, O. (2003). Empty ethics: the problem with informed consent. *Social Health and Illness* 25(7):768-792, <https://doi.org/10.1046/j.1467-9566.2003.00369.x>
- Davis, R.M., Hitch, A.D., Nichols, M., Rizvi, A., Salaam, M., & Mayer-Davis, E.J. (2009). A collaborative approach to the recruitment and retention of minority patients with diabetes in rural community health centers. *Contemporary Clinical Trials*, 30(1), 63-70. <https://doi.org/10.1016/j.cct.2008.09.007>
- Fong, M., Braun, K.L., & Tsark, J.U. (2003). Improving Native Hawaiian health through community-based participatory research. *Californian Journal of Health Promotion*, 1(SI), 136-148.
- Fong, M., Braun, K.L., & Chang, R.M. (2004). Native Hawaiian preferences for informed consent and disclosure of results from research using stored biological specimens. *Pacific Health Dialog*, 11(2), 154-9.
- Fouad, M.N., Partridge, E., Green, B.L., Kohler, C., Wynn, T., Nagy, S., & Churchill, S. (2000). Minority recruitment in clinical trials: a conference at Tuskegee, researchers and the community. *Annals of Epidemiology*, 10(8), S35-S40. [https://doi.org/10.1016/s1047-2797\(00\)00199-x](https://doi.org/10.1016/s1047-2797(00)00199-x)
- Galinsky, A., Zelaya, C., Barnes, P., & Simile, C. (2017). Health conditions of Native Hawaiians and Pacific Islanders in the United States: Data from the Native Hawaiian and Pacific Islander National Health Interview Survey (NHPI NHIS). In *APHA 2017 Annual Meeting & Expo (Nov. 4-Nov. 8)*. American Public Health Association.
- Geller, S.E., Koch, A., Pelletieri, B., & Carnes, M. (2011). Inclusion, analysis, and reporting of sex and race/ethnicity in clinical trials: have we made progress? *Journal of Women's Health*, 20(3), 315-320. <https://doi.org/10.1089/jwh.2010.2469>
- Gollin, L. X., Harrigan, R.C., Perez, J., Easa, D., & Calderón, J.L. (2005). Improving Hawaiian and Filipino involvement in clinical research opportunities: qualitative findings from Hawai'i. *Ethnicity & Disease*, 15(4 Suppl 5), S5.
- Harrigan, R., Perez, M. H., Beaudry, S., Johnson, C., Sil, P., & Apau-Ludlum, N. (2014). Recruitment and retention of under-represented groups with health disparities into clinical trials: A formative approach. *Journal of Immigrant and Minority Health*, 16(5), 898-903. <https://doi.org/10.1007/s10903-013-9786-8>
- Hawai'i Tumor Registry, *Cancer at a Glance in Hawai'i: 2009-2014*. University of Hawai'i Cancer Center (2016). https://www.uhcancercenter.org/pdf/htr/Hawaii%20Cancer%20at%20a%20Glance%202012_2016.pdf
- Hirano, S.A., Murray, S.B., & Harvey, V.M. (2012). Reporting, representation, and subgroup analysis of race and ethnicity in published clinical trials of atopic dermatitis in the United States between 2000 and 2009. *Pediatric Dermatology*, 29(6), 749-755. <https://doi.org/10.1111/j.1525-1470.2012.01797.x>
- Hixson, L, Hepler, B.B. & Kim, M.O. (2012, May). *The Native Hawaiian and Other Pacific Islander population: 2010* (2010 Census Briefs). US Department of Commerce, Economics and Statistics Administration, US Census Bureau. Report Number C2010BR-12
- Hughes, C.K. (2004). Factors associated with health-seeking behaviors of Native Hawaiian men. *Pacific Health Dialog*, 11(2), 176-182.

- Ka'ano'i, M., Braun, K.L., Gotay, C.C., & Abrigo, L. (2002). Oncologists' knowledge, attitudes and practices related to cancer treatment clinical trials. *Hawaii Medical Journal*, 61(5), 91.
- Ka'ano'i, M., Braun, K.L., & Gotay, C.C. (2004). Primary care physicians' knowledge, attitudes and practices related to cancer screening and cancer prevention clinical trials. *General Practice*, 73, 29.
- Kaholokula, J.K.A., Saito, E., Mau, M.K., Latimer, R., & Seto, T.B. (2008). Pacific Islanders' perspectives on heart failure management. *Patient Education and Counseling*, 70(2), 281-291. <https://doi.org/10.1016/j.pec.2007.10.015>
- Kaholokula, J.K.A., Ing, C.T., Look, M.A., Delafield, R., & Sinclair, K. I. (2018). Culturally responsive approaches to health promotion for Native Hawaiians and Pacific Islanders. *Annals of Human Biology*, 45(3), 249-263. <https://doi.org/10.1080/03014460.2018.1465593>
- Ka'opua, L.S. (2003). Training community practitioners in a research intervention: practice examples at the intersection of cancer, Western science, and Native Hawaiian healing. *Cancer Control* 10(5 Suppl):5-12. <https://doi.org/10.1177/107327480301005s02>.
- Ka'opua, L.S. (2008). Developing a culturally responsive breast cancer screening promotion with Native Hawaiian women in churches. *Health & Social Work* 33(3):169-77. <https://doi.org/10.1093/hsw/33.3.169>
- Look, M.A., Trask-Batti, M.K., Agres, R., Mau, M.L., & Kaholokula, J.K.A. (2013). *Assessment and priorities for health & wellness in Native Hawaiians & Other Pacific Peoples*. Honolulu, HI: Center for Native and Pacific Health Disparities Research, University of Hawai'i at Manoa. https://www2.jabsom.hawaii.edu/native/docs/community/DNHH_Assessment&Priorities_Report_2013.pdf
- Mokuau, N., Braun, K.L., Wong, L.K., Higuchi, P., & Gotay, C.C. (2008). Development of a family intervention for Native Hawaiian women with cancer: A pilot study. *Social Work*, 53(1), 9-19. <https://doi.org/10.1093/sw/53.1.9>
- Murthy, V.H., Krumholz, H.M., & Gross, C.P. (2004). Participation in cancer clinical trials: race-, sex-, and age-based disparities. *JAMA* 291(22), 2720-2726. <https://doi.org/10.1001/jama.291.22.2720>
- OnCore/CTMS. Oncore Clinical Trials Management Systems.
- Parra-Medina, D., D'Antonio, A., Smith, S. M., Levin, S., Kirkner, G., & Mayer-Davis, E. (2004). Successful recruitment and retention strategies for a randomized weight management trial for people with diabetes living in rural, medically underserved counties of South Carolina: the POWER study. *Journal of the American Dietetic Association*, 104(1), 70-75. <https://doi.org/10.106/j.jada.2003.10.014>
- Patton, M.Q. (2014). *Qualitative research and evaluation methods*. 3ed. London, UK: Sage Publications.
- Pokhrel, P. & Herzog, T.A. (2014). Historical trauma and substance use among Native Hawaiian college students. *American Journal of Health Behavior* 38(3):420-429. <https://doi.org/10.5993/AJHB.38.3.11h>
- Santos, L. (2008). Genetic research in native communities. *Progress in Community Health Partnership: Research, Education, and Action* 2(4):321-7. <https://doi.org/10.1353/cpr.0.0046>

- Skaff, M.M., Chesla, C.A., de los Santos Mycuc, V., & Fisher, L. (2002). Lessons in cultural competence: Adapting research methodology for Latino participants. *Journal of Community Psychology* 30(3):305-323. <https://doi.org/10.1002/jcop.10007>
- Townsend, C.K., Dillard, A., Hosoda, K.K., Maskarinec, G.G., Maunakea, A.K., Yoshimura, S. R., Hughes, C., Palakiko, D., Kehauoha, B.P. & Kaholokula, J.K.A. (2016). Community-based participatory research integrates behavioral and biological research to achieve health equity for Native Hawaiians. *International Journal of Environmental Research and Public Health*, 13(4):1-10. <https://doi.org/10.3390/ijerph13010004>
- U.S. Census Bureau. (2018). Asian and Pacific Islander Population in the United States (2018), *American Community Survey 1-Year Estimates*, Table BO2018. <https://www.census.gov/library/visualizations/2018/comm/api.html?cid=api-graphic>