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## Health literacy, health communication challenges, and cancer screening among rural Native Hawaiian and Filipino Women

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### Abstract

Native Hawaiians and Filipinos are disproportionately impacted by cancer, and are less likely to participate in cancer screening than whites. Limited information exists about health information pathways and health communication challenges as they relate to cancer screening in these groups. Six focus groups (n=77) of Native Hawaiian and Filipino women age 40+ years were conducted to investigate these research gaps. Participants noted many health information challenges. Challenges were both practical and interpersonal and included both written and oral health communication. Practical challenges included “big” words, complexity of terms, and lack of plain English. Interpersonal issues included doctors rushing, doctors not assessing comprehension, and doctors treating respondents as patients not people. Women noted that they would often not ask questions even when they knew they did not understand because they did not want the provider to think negatively of them. Overarching themes to improve cancer communication gaps included: (1) the importance of family and community in health information dissemination; (2) the key role women play in interpreting health information for others; (3) the importance of personal experience and relationships to the salience of health information; and (4) the desire for local cultural relevance in health communication. Findings are discussed in light of the 2010 National Action Plan for Health Literacy.

### Introduction

Native Hawaiian and Filipino women are disproportionately impacted by cancer mortality [1, 2, 3]. The effectiveness of routine screening for breast, cervical, and colorectal cancer in reducing cancer mortality is well established [3]. Yet cancer screening use is lower for Native Hawaiian and Filipino women than for many other racial/ethnic groups [4, 5].

Despite the cancer disparities experienced by Native Hawaiians and Filipinos, limited information exists about the health information needs, health literacy, and health communication challenges in general and in relation to cancer among these groups [6]. Also, little is known about this topic from the perspectives of individuals from these distinct cultures, although it is critical to understand cultural context in cancer education efforts [7]. Previous research with Native Hawaiians and Filipinos in Hawai'i suggests that these groups have distinct preferences regarding health information dissemination in general and

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Conflict of interest

The authors declare that they have no conflicts of interest.

specifically in relation to cancer screening [8, 9, 10]. Greater knowledge of health information challenges and preferences among Native Hawaiians and Filipinos can help improve and tailor cancer education for these vulnerable ethnic groups.

The study goal was to address these knowledge gaps by obtaining qualitative data about health information needs, health literacy, and health communication challenges generally and specifically regarding cancer screening among Native Hawaiian and Filipino women in rural communities. We focused on individuals in rural communities due to lower prevalence of cancer screening in this population, and the need to increase cancer screening and improve outcomes among rural populations [8, 9].

## Methods

Six focus groups included 77 Native Hawaiian and Filipino women age 40 years or older in rural settings on four Hawaiian islands. One group was conducted on Maui, one on O'ahu, and two each on the islands of Moloka'i and Hawai'i. Both the University of Hawai'i and the Native Hawaiian Health Care Systems Institutional Review Boards approved the study.

Community agencies in rural communities were subcontracted to assist with participant recruitment and focus group logistics. In the week preceding the focus group, participants were consented by community partners and completed a brief questionnaire including questions on: (1) basic demographics (age, race/ethnicity, education, sex, insurance status, marital status, born in the US); (2) self-reported health literacy; (3) family and personal history with cancer; and (4) cancer screening history (colorectal, cervical, and breast). During the hour directly preceding the focus group, a brief one-on-one health literacy assessment was administered by a member of the research team with each participant, which included the Short Test of Functional Health Literacy in Adults (S-TOFHLA) [11].

Focus groups were conducted by a trained focus group facilitator of Filipino heritage who was raised in Hawai'i, married into a Native Hawaiian family, and familiar with Hawai'i's rural communities. Focus groups lasted about 90 minutes. After an icebreaker exercise to increase the comfort level of participants, discussions centered around: (1) sources for health information generally, and cancer screening health information specifically; (2) challenges with health information; (3) who participants helped with health-related information; (4) who helped participants when they had trouble understanding health information; (5) barriers to cancer screening for participants and for Native Hawaiians and Filipinos in general; and (6) suggestions of materials or modes of information that would help participants better understand cancer and cancer screening and would increase the salience of this information (Table 1). Refreshments were provided, and participants received a \$25 gift card to a local variety store. Focus groups were tape-recorded and then transcribed, a process enhanced by detailed field notes taken during the sessions.

The framework approach [12] was used for analysis as focus group questions were based on pre-set aims. Following the five steps of the framework approach (familiarization, developing a codebook, coding, charting, and interpretation), the investigators read the transcripts to become familiar with the raw data and to identify key ideas and recurrent themes derived from the study aims and from focus group respondents [12]. A code book was created, and transcripts were systematically coded by two investigators (TS, HHH). Reviewers were not concordant on <5% of the codes, and these discrepancies were resolved through discussion among three researchers (TS, HHH, and KB) [13]. Data then were charted (i.e., rearranged and synthesized) into core themes (Table 2). In the interpretation phase, key quotes were identified that illustrated these themes. Data on sample

demographics, health literacy, and health information sources were analyzed using Stata 12 [14].

## Results

Presented in Table 3 are sample characteristics by focus group location. Overall, 64% of the participants reported their primary ethnicity as Native Hawaiian and 36% as Filipino; 86% of the Native Hawaiians were born in the US, along with 36% of the Filipinos. Forty percent of women were between the ages of 40-49 years, 48% were between 50-64 years, 10% were over 65. The majority (69%) reported a high school degree or some college, and 25% had a 2-year college degree or higher. On the S-TOFHLA, 12% scored below adequate health literacy, including 18% of the Filipinos and 8% of the Native Hawaiians. However, a notable difference in health literacy can be seen in health literacy across the focus group sites with three having <10% low health literacy and three having >18% low health literacy. Considering cancer screening, 11% of the sample had never had a mammogram and 5% had never had a Pap smear; 17% were cancer survivors.

### Health Information

**Sources for Health Information**—Women received general health information in three key ways: (1) from personal communication within the health care system, (2) from personal communication outside the health care system, and (3) from media, including the internet and print material. Within the health care system, the most common source of health information was the doctor, a source highly endorsed across all focus groups. (Specific information regarding the number of times common subjects, including doctors as sources of health information, were mentioned across focus groups can be found in Table 2.) However, many other providers and health-related locations were also mentioned at least once as examples of important health information resources, including pharmacists, the doctor's staff, nurses, hospitals, community health clinics, women-focused health clinics, Native Hawaiian healers, sex educators, and the emergency room. One rural community in particular endorsed health fairs as a source of health information. Advantages of this approach were described by one participant:

“You need events to draw people out, or else they would not pursue the information by themselves. The community can be shy or ashamed to ask, but when it is out in the open, it makes it more comfortable to receive information.”

Outside the health care system, family, friends (especially female friends), and the community played a critical role in the dissemination of health information. In discussions, participants mentioned that a key source of health information was a family member or friend who worked within the health care system, bridging across, “inside” and “outside” the health care system. For instance, one participant noted that she would, “...ask my two kids, my daughter's a nurse and the other works in health care” for health information, and another noted, “My cousin is in the health field, so sometimes I call him.” Participants also mentioned, “kupuna” (elders) and coworkers as key sources for health information in the community.

Media sources were also mentioned, included pamphlets, mailings, television, magazines, store bulletin boards, and newspapers. The most common media source for health materials was the internet, mentioned across all focus groups. Challenges in obtaining health information from the internet were also mentioned in all groups, including the fact that not every household has access to the internet. As one women mentioned, you can only easily access the internet, “if you're lucky enough to have a computer,” a statement echoed by an “Amen!” by another participant. Also, the vast sea of information found on the internet was

a common complaint. This is shown by the following quote by a woman who expressed frustration when she was asked to go on the internet if she wanted to learn more about her health condition:

“Sometimes you go to the website, and they have so much different information on it, and it doesn’t jive to what they are telling you at the office. And you go to a website and they bring up how many of them, and you gotta try and click, and, oh no that’s not it! You go to the next one, no that’s not it! You know, it’s hard.”

**Who participants helped with health care information**—These women, predominantly between the ages of 40-65, were at the nexus of health information for their families, and 25 examples of helping a family member with health information were given during focus groups. Women provided help to aging parents, their own children (many of whom were grown and had children), and their grandchildren (whom many of them cared for). One woman also provided health information for an elder community member. Their role as the assistant with their parents’ health information, in particular, could be complex. A number of women noted that they had elderly parents who were part of a generation and culture that is not likely to ask questions of a doctor or to indicate that they did not understand what a doctor or nurse said. Participants said their parents expected them to figure out the answers to questions that their parents did not ask about during the doctor’s appointment, often leaving them in an uncomfortable role, as in this example (one of four):

‘My parents are old and they expect you to do things for them because you already went through it. They ask me to call in their prescriptions and then they ask, “What did they say?” even though they already went to the doctor and they know what it is, you have to break it down and tell them, “Okay, you no can eat, you no can this...” Then they ask, “Oh, what about if I drink?” They ask questions like they are kids and you have to go through it with them. But a lot of the time they aren’t really thinking about it and end up taking their medication incorrectly.’

### Health Information Challenges

Women reported a number of challenges with health information. These challenges were both practical and interpersonal and included both written and oral health communication. Practical challenges included “big” words, complexity of terms, and lack of plain English-- issues that were heavily endorsed (>10 times) across all focus groups. Women particularly noted the lack of information in plain English, mentioning problems with “doctor language” and “medical terms.” Other practical challenges included: small print, the complexity of materials related to medications and health insurance, and the overwhelming volume of health information, all of which were discussed by women in two or more focus groups. As noted previously, women were very aware of both the advantages and limitations of health information online. Although practical issues were mentioned in all groups, they were identified more often by women in the three groups with higher health literacy than by women in the three lower health literacy groups. Women also discussed the importance of language. For example, there are no words for some medical conditions and treatments in Tagalog, Ilocano, or Visayan (three main Filipino dialects in Hawai’i). As mentioned by a participant, “If it’s not in their language they might be afraid to ask.” Other issues mentioned, but less commonly, included lack of reading ability and doctors’ poor handwriting, which was mentioned three times.

Interpersonal issues also complicated health information exchange. Participants mentioned many interpersonal issues within the patient-doctor communication, including the fact that doctors are often in a rush, that they had pamphlets but did not take the time to explain them, that doctors would not ask them if they understood, and that doctors did not treat them like

individuals. Women in the three focus groups with higher percentages of low health literacy particularly noted the interpersonal issues with doctors (13 mentions in these three groups compared to only 1 mention in the other 3 groups). These issues could make patients avoid verbal communication with their providers since patients perceive their questioning would be viewed negatively by providers. Women noted that they would often not ask questions even when they know they do not understand, as typified in this quote:

“Sitting in the doctor’s office and sitting there like you know what he is talking about, and not knowing one crappy thing that he has said or she just said, and walk out saying to yourself, “What wrong with me?” You come out of there, plus part of it comes from you don’t want to sound stupid, and you know he’s so in a rush, or she’s so in a rush to get out of there.”

Women noted that health information is more comprehensible when a personal connection or a feeling of a personal relationship is made with a health care provider, but they were concerned that the time for this personal connection may come with cost, either for a separate visit to their doctor or to another provider. The complicating factors of being sick, and stressed about being sick were mentioned, and the challenges of processing new information in the face of bad news was also mentioned across multiple groups. A further issue mentioned across all focus groups (10 times total) was how much participants were forced to advocate for themselves in regard to their own health or that of their families.

“You know, so you need to advocate for yourself, and ask the questions, and tell them, you know, “Is it safe? Are you telling me I can do this? Are you telling me I shouldn’t do this? What should I do?”

This responsibility was noted four times relating specifically to the role that these women play as a key source of health information for their family members, as in the example:

“My mom takes almost seven different medications per day in different amounts and different things, and we [respondent and her sister] had to learn about each one and make sure that anything new coming in or anything over the counter won’t mess it up [Murmurs of agreement from others]. And that scared the hell out of us when we started figuring that out. We didn’t know. We just had to start learning. It wasn’t all, ‘Here you got seven new medications. Take them.’ One at a time? Two at a time? [Murmurs of agreement.] At night? In the morning? They [the medicines] started coming in, and you have to figure it out. It was scary.”

### Cancer Screening Context

**Familiarity with cancer screening**—Most women who participated in these focus groups had relatively high health literacy, high engagement with the health care system, and health knowledge. Almost all women were very familiar with mammograms and Pap smears. While many were not familiar with the term “clinical breast exam,” they recognized the procedure when it was explained. The one area they were less knowledgeable about was colorectal cancer. Only a few women in each group were familiar with fecal occult blood testing (FOBT), and even fewer women were familiar with the flexible sigmoidoscopy. Of the colorectal cancer screening options discussed, colonoscopy was the most familiar, although many women remained unfamiliar with it across the groups. Of those who were familiar with the FOBT, many expressed both a strong dislike for the test and challenges with the instructions, such as this respondent:

“[I disliked it] because then I have to keep going and hauling that thing out, and then I forgot to bring it in with me [to the bathroom]. And then I had to go back to the doctors, and they said, “How come you only filled out two?” And I said

because I had a problem remembering to take it in with me...And I figured, why can't we just do this at the office?"

**Why Native Hawaiian and Filipino women do not get screening tests**—When asked about why they thought Native Hawaiian and Filipino women do not get the recommended cancer screenings, participants had many ideas, including personal/cultural barriers, practical barriers, knowledge-related barriers, priority-related barriers, and test-related barriers. Personal/cultural barriers included perceptions that the test is too invasive and/or scary, the emotional nature of the test, and privacy issues. Practical barriers included cost and access to care. Test-related barriers included the time taken for preparation or to receive the test. Knowledge-related barriers included reasons related to health literacy, such as reading skills:

“In the doctor’s office, on the wall, there’s just... the assumption is that everybody can read. That’s the assumption that doctors have or nurses have, in the office. But not everyone can read.”

Also respondents discussed a lack of understanding regarding the importance of screening. These barriers did not work alone, but in concert, as in the following example where knowledge-related barriers are coupled with the many practical and personal barriers to screening:

“There is a cultural barrier still, and the language differences...there are still people who are afraid to come out and ask for help because everything, when it comes to medical stuff, its expensive, and people can’t afford it. They don’t want to burden their family with it too, but it’s the lack of understanding, the lack of understanding how important some of these things are, that it’s life altering.”

Participants also mentioned they did not know why they need it or where to go or what is available, saying women do not go, “...because they’re thinking they don’t have any symptoms, so their health is excellent. They don’t feel the need to go,” or “They’re not educated about it. They don’t know that there’s screenings available.”

## Solutions

**Strategies to understand health care information**—Women suggested strategies to improve health information in terms of better ways to present health information, in terms of relationship-based solutions, and in terms of their own practical strategies to deal with complex health information. For presenting health information, respondents clearly felt that more plain language and lay vernacular would improve health communication. One woman was happy that her “doctor explains in a lot of words but in very simple words—layman’s terms.” Other popular suggestions were to use show-and-tell and to include more pictures. One woman summarized this concept in her quote, “Use more pictures. I think the people don’t read that much.”

For relationship-based strategies, women also had a number of people they would turn to for help with complicated health information. The community, family, and friends, especially those who worked in health care, were important sources of help. Also mentioned were physicians’ receptionists and pharmacists, who were described as “very helpful and will answer questions.” Women also felt that patient-centered relationship could improve health communication, including working with the physician as a team.

‘If they could break it down where it’s more understandable for us. We’re a lay person. And we just want to be able to understand what he’s [saying]. At least comfortable, talk story. When you are not feeling well and you’re sick and you’re stressed out, you don’t want to hear any medical terms. You want to hear

something like, “I know you have cancer, but it’s going to be ok because we can work through it together.” You know, the bedside manner speaks loudly. And if they can, you know... I can appreciate someone who can come up and talk to me and say, tell me, “Excuse me, I’m sorry, but I don’t know anything about your cancer, but I will get on it.” And when he says I’ll get back to you, it would be really nice if they did get back to you. You know, and... but for them to be human, and say, “I’m sorry, but I don’t know the answer.” And that’s good, because I know the cancer I have, not very many do people know about it. But when you say, “I’ll get back to you,” please do.’

Specific strategies that women use to deal with complex health information were brought up eight times across four focus groups. These emphasized the importance of being ones’ own advocate as described by this participant: “If I don’t understand the word, I will ask the doctor for a breakdown in plain English” or this one: “I won’t leave the doctor until I understand.”

**Strategies to improve cancer screening**—Respondents shared many ideas to improve cancer screening in their communities. These were of several types: relationship, community, procedure, information, access and media-based. Across types of solutions, the most common suggestions were: (1) Friends helping friends; (2) Family helping family; (3) “Talk story” activities; (4) Starting cancer awareness education at a younger age, especially in schools, so these issues will be familiar to individuals over the lifespan, rather than a new topic in their 40s and 50s; (5) Making the procedures simpler, particularly FOBT, and (6) Reducing practical barriers, including cost and transportation. These solutions, all but one outside of the health care system, indicate the importance of community support and social networks as personal health resources. One woman noted:

“I think people really don’t know what’s available as far as treatment. They don’t know what the next steps are and stuff. So last October we pulled a group together, and then we had resource people, somebody from outside, come. She was excellent. She battled cancer, breast cancer. It was so awesome because you went in not knowing anything, but you came out knowing that you should do this, you should be doing self-examinations. This is how you do it. I mean, she was really graphic. And she shared a whole lot. That’s the kind of talk story stuff...with pictures and everything.”

Another woman said:

“If someone I know already has cancer, I know I can go to them for advice. Getting advice from someone I know has experienced cancer makes the information more urgent and trustworthy. I am more likely to act upon advice because I can see someone close to me suffering from the disease. It becomes real for me and makes me internalize it.”

Personal experience was a motivator for screening. As one respondent said, when asked why she got screened: “My grandma, in the mid 60s, had breast cancer, so I knew. My mom and my grandma always reminded us that us girls were at risk, and so I was always aware of it, and it’s because of experiences like that.”

Participants who were cancer survivors were quite cognizant of the important of their experience for others seeking their advice. For instance:

‘Whenever you are talking to your family member about a medical procedure it can be scary, so if you have already gone through it you can guide them. Then you can just say, “Let’s go.” I had a mastectomy, so it’s not hard to get my family and friends to go.’

The friend and family intervention ideas included festive events. Women liked the idea of attending screening with family and friends. This suggestion was mentioned over twenty times. Participants even suggested including mammography screening at celebratory venues, “like bridal showers.” Other suggestions were using tactile materials and videos in education.

Filipino participants felt the inclusion of local language and a local messenger (“someone’s out there explaining it in their own language”) would be helpful. Also suggested were culturally relevant media that included local faces and information relevant to Filipino and/or Hawaiian ethnic groups. Several Native Hawaiian women noted that they appreciated cancer education materials developed by and for Native Hawaiians that were being distributed by a local program. They were unaware if similar materials existed for Filipinos. One woman who indicated surprise that screening rates were lower in her racial/ethnic group felt this was important information to share with the community to motivate women to get screened.

‘Because that’s news to us, for me, that you said that the least one getting this screenings is Hawaiians and Filipinos. I mean, I didn’t know that til you said it. So maybe that kind of information [to share to motivate screening] like she says on a commercial or something, like “what?” so people will be like, we better step ourselves up a little bit.’

Interestingly, only one participant in all the focus groups mentioned an individually-focused (“self-discipline”) strategy to increase screening.

## Discussion

A number of important social and cultural themes emerged from this research that can help improve cancer education and information dissemination among Native Hawaiians and Filipino women. Foremost is the importance of family, friends, and community (including coworkers) in the understanding of and dissemination of health and cancer information. This was discussed multiple times in every focus group. Another critical theme was the role of personal experience and relationships to the salience of health information and as a motivator and source of trustworthy information. The final critical theme was the importance of local context in materials, providers’ knowledge, and screening options. Women specifically noted this preference in terms of the desire for culturally, and locally, relevant materials as well as a stated desire for providers to have a strong understanding of local community context.

These themes suggest that interventions to improve cancer screening should take advantage of “go to” and trusted sources within family, friendship, and community networks. They also suggest that these women, especially cancer survivors, could be potentially employed as messengers within their communities, building on their clear role as sources of health information because of their experience. These women may have more opportunities to encourage their peers and family members to get screened in ways that ensure local cultural understanding, an important factor for respondents. They may be particularly able to relate to community concerns and barriers to screening. For instance, the second most commonly noted barrier to cancer screening was the desire for privacy, coupled with the concern that cancer screening is “invasive” and “scary.” Local women could speak directly to these concerns, with an implicit understanding of cultural norms within communities. For example women noted that cancer screening could be considered “private family business” and asked “why would you tell an outsider?” about these issues. Programs that promote and educate about the importance of cancer screening should build in opportunities to train and employ



women from the community and partner with existing community networks, such as including women from the community in support groups and screening outreach.

At the same time, women indicated they would be willing to bring cancer screening into personal activities like wedding showers. While bringing cancer screening into intimate personal events may not be plausible in many cases, these suggestions indicate that cancer-related health is important enough to these women that they were willing to entertain the idea of incorporating it into personal celebrations. Creating festive community opportunities for screenings that draw upon respondents' stated preferences to integrate this with personal relationships and celebratory occasions may be fruitful.

This research also better illuminates health information needs, health literacy, and health communication challenges among rural Native Hawaiian and Filipino women, supporting existing research [8, 10] and programs [9, 15] that seek to improve cancer knowledge and address cancer disparities among these populations. Health literacy is useful to consider. Native Hawaiians and Filipinos in Hawai'i have a higher prevalence of self-reported low health literacy than the other major racial/ethnic groups in Hawai'i, with Filipinos having a particularly high rate of low health literacy [16]. Having low health literacy is associated with less understanding of, and less participation in, cancer screening, as well as more advanced cancer at detection, even after controlling for age, education, and insurance status [17, 18]. While overall the rate of low health literacy was low, three focus groups had relatively high rates (>18%) of low health literacy and three had relatively low rates (<10%). Most response patterns were similar across groups, although practical communication challenges (small print, big words) were mentioned more in the higher literacy groups, while communication challenges associated with poor interpersonal relations with physicians were mentioned more in the lower literacy groups. Yet across all groups, even in groups with relatively high health literacy, respondents noted many ways they felt unable to fully obtain, process, or understand critical health information.

Respondents also noted a wide range of practical and cultural barriers that limited their ability to fully understand health information. Practical barriers to health information included confusing forms and instructions, insufficient time and incentives for patient education, overuse of medical and technical terms to explain vital information, the need to be a self-advocate, equal access to information (e.g., some do not have computers; some live far from health centers that provide health information), and the complexity of information related to medications, side-effects, and health insurance. Cultural barriers to health information encompassed differences in language, cultural norms and preferences, and patients' expectation toward patient-doctor relationship. At the same time, many women were responsible not only for information about their own health, but also for that of their family members, many of whom had multiple medical conditions and medications.

Overall, the complexity of health information and a strong desire for plain language in health information was expressed across all groups. To overcome these barriers, many respondents of our study seek help from their kinship (family and relatives) and non-kinship (friends and community) networks. Providing information to local health care workers, including lay health workers, to share with their community, and also drawing upon survivors within communities to provide peer education, may help to address these concerns. Also, it is essential to continue to make providers aware of these issues and to work towards reducing the health information challenges of paperwork and systems navigation.

While the 2010 Plain Writing Act [19], which requires "clear government communication that the public can understand and use," was an important step forward for efforts to

improve plain language in health, this alone is not enough to address the stated needs of participants. Another relevant recent federal effort is the 2010 National Action Plan to Improve Health Literacy (NAP) [20], which directly addresses a number of the concerns voiced in these focus groups, with great relevance to cancer information dissemination [21]. The findings of this study support the implementation of NAP recommendations, and many focus groups discussions precisely echoed both the issues and solutions described in the NAP, including community context, user-centered design, and universal precautions.

Community was central to focus group participants. The NAP indicates that: “Communities play a central role in supporting efforts to improve health literacy. Emphasis should be placed on community opportunities for communication, education, and peer support surrounding health information seeking and access to care.” [22] Community-focused health information sessions, both health fairs and talk-story sessions, were particularly appealing to participants. Such efforts were spontaneously described across many focus groups and are congruent with individual, community, and cultural preferences expressed in focus groups.

User-Centered Design, including members of the target audience in the creation of health materials, can improve health outcomes generally and specifically for those with low health literacy [10, 15, 20]. Native Hawaiian and Filipino women in rural communities had specific preferences, including the desire to talk story, to include the community, and to represent their own cultural context, including local faces and local languages. Receiving this guidance about solutions from Native Hawaiian and Filipino women themselves is very important. This study confirms that the effectiveness of health education messages can be improved by engaging community in the design of materials and in peer education, as well as addressing practical barriers to health access such as cost and transportation. One preference mentioned was the desire for pictures in health education. Visual images are particularly important for those with low literacy, though all patients tend to benefit from them [22]. Published guidelines suggests that pictures should be used to support key points, should be concrete rather than complex, should be free of unnecessary details and should be linked tightly to text. Pre-testing is also important to ensure comprehension and cultural appropriateness [22].

The NAP also discusses the importance of a Universal Precautions Approach; “even though everyone will not be at the same health literacy level, it is always best to use the clearest language possible.” [20] The utility of this approach was very clear within these focus groups. While most women had adequate health literacy, many health information challenges were noted along with a strongly desire for concise, easy-to-read information with clear languages.

## Limitations

Only 12% of the study sample scored below adequate health literacy according to the S-TOFHLA, although three focus group sites had more participants with low health literacy than the other three sites. This may have been a function of recruiting through existing social or service groups, which may attract individuals curious about health and attentive to health information. Considering that rural and minority groups typically have lower health literacy than average [23], the percentage of Native Hawaiian and Filipino women with adequate health literacy was higher than expected in several groups. Whether this is due to higher health literacy rates among Native Hawaiian populations or because many of our focus groups were drawn from existing cancer support networks (17% had a cancer history) is not known. Across focus groups, there was no obvious association between cancer history and health literacy score. Because of our overall low rates, our study may underestimate the health information needs of Native Hawaiian or Filipino women who are either less integrated with the health care system and/or who have lower health literacy. The fact that

health literacy and health information issues were mentioned numerous times across focus groups indicates the great need for easier-to-understand health information across the health care and public health systems. At the same time, it is worth noting that women who were already integrated in the health care system remained hungry for health information. In a number of focus groups, individuals discussed the need for better information that applied directly to them, and the failures of the internet, the doctors' office materials, and the community to fully provide that information. Another limitation was that our study was focused on qualitative analyses and did not provide a quantitative analysis of the association between low health literacy and cancer screening among respondents.

## Conclusions

Native Hawaiian and Filipino women in rural communities, even in focus groups with high numbers with adequate health literacy, expressed multiple challenges in health communication and health literacy. Major findings included: (1) the importance of family and community in health information dissemination; (2) the key role these women play in helping their families, especially elderly parents, interpret health information; (3) the critical importance of personal experience and relationships to the salience of health information; and (4) the desire for local cultural relevance in health communication. These can be drawn upon to improve health information and cancer education for rural Native Hawaiian and Filipino women with the ultimate goal to decrease cancer health disparities in these vulnerable populations.

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**Table 1**

## Focus Group Questions

1.	Where is the main place or person you would go to in order to get advice or information about your health or your family's health?
2.	Sometimes it is difficult to understand health information. Could you describe any challenges you have had understanding health information?
3.	Who in your family asks you for help understanding health information? What do they need help with? What kind of help do they need?
4.	How often do you ask for help understanding health information? Who do you ask for help? What do you need help with? What kind of help do you need?
5.	Is there anything that could make health information easier for you or your family members to understand?
6.	Now we are going to talk about a specific kind of health information. Where would you go to get information about cancer?
7.	How many of you have heard about a <u>mammogram</u> (clinical breast exam, PAP Smear, FOBT, Double Contrast Barium Enema, Flexible Sigmoidoscopy <u>Colonoscopy</u> )? [Number counted, process described briefly and then count asked again.] Who or where did you hear about this test?
8.	Many Hawaiian and/or Filipino women do not get screening tests as often as many other women in Hawai'i. Why do you think that is?
9.	Is there any health information that you think would help Hawaiian and/or Filipino women to get more cancer screening tests so they can find the cancer early? What is it?
10.	We had some cancer information on the tables. Can you share what you picked up and why?

Table 2

## Major Themes by Topic Area

Topic Area	Major Themes	Times Mentioned	Most common examples (# times mentioned)
<b>General Health Information</b>			
<b>Sources of Health Information</b>			
	Communication within health care system	62	Doctor (35), Community Health Clinics (8), ER/Hospitals (4), Pharmacist (2), Office Staff (2)
	Media	45	Internet (18), Media/TV/Radio (12), Pamphlets (8)
	Communication outside health care system	29	Friends/Community (15), Family (12), Kupuna (2),
<b>Health Information Challenges</b>			
	Practical	71	Big words/Plain English (14), Complexity of health information (12), Overwhelming information (12), Internet-related challenges (11), Small print (10)
	Interpersonal	30	Doctor-related challenges, e.g. doctor in a hurry, doctor doesn't explain (15); Have to advocate for self (10), Shame/embarrassment about not understanding (7)
	Community	5	Needed information is not in the community now (3) or historically (2)
<b>Cancer Screening Information</b>			
Why Native Hawaiian and Filipino women don't get screened			
	Personal/Cultural Barriers	31	Scary (9), Shy/private (8), Shame (4), "Cultural barrier" (2)
	Practical Barriers	14	Cost (8), No insurance (4), Other access (2)
	Knowledge-Related barriers	13	Doctor didn't say so/no reminder (3), Don't know why need it (3), Don't want to know (3)
	Priority-Related barriers	11	Denial (7), No time (6), Time slips away (2), No symptoms (3)
	Test related barriers	7	Pain/Discomfort (4), Challenge of Prep (3)
<b>Solutions</b>			
<b>Solutions to better understand health care information</b>			
	Ways of showing information	33	Pictures (9) Plain language (6), More concise (5)
	Relationships	30	Talk story (9), Interact face-to-face (6), More explanations (4), Doctor outside clinic setting (3)
	Practical strategies	8	Use websites (2), Don't leave until understand (2), Record doctor's words (1)
<b>Solutions to improve cancer screening in NH and Filipino communities</b>			
	Relationship-based	40	Friends helping friends (14), Family helping family (11), Group activity/Talk story (9)
	Community-based	39	Put in schools/Start young (22), Personal, Repeated Reminders (10) Rally Community (3)
	Procedure-based	35	Make procedure simpler (22), Make more comfortable/less painful (10)
	Communication/Information -Based	29	Explain in own language (8), More education (7), Tactile Materials (3), Explain Options (3)
	Access-based	21	Make free (3) Transportation (1)
	Media Based	4	Videos (3); Facebook/Social media (1)

Table 3

## Demographics by Focus Group

	Location	% Age 40– 49	50– 64	65+	% Hawaiian	% Filipino	% Low Health Literacy	% Cancer History	n
1	Moloka'i	69	25	6	56	44	0	19	16
2	Moloka'i	63	31	6	64	36	6	6	16
3	Hawai'i Island	9	73	18	91	9	18	45	11
4	Hawai'i Island	10	80	10	100	0	20	10	10
5	Hana, Maui	8	69	15	77	23	8	23	13
6	Rural O'ahu	64	27	9	0	100	27	0	11

<sup>1</sup>One participant did not give age