

Increasing participation in cancer research: insights from Native Hawaiian women in medically underserved communities

Abstract: The cancer burden falls heavily on Native Hawaiian women, and of particular concern are those living in medically underserved communities where participation in potentially helpful clinical studies may be limited. Difficulty in accrual of Native Hawaiian women to a culturally-grounded intervention led researchers to conduct focus groups aimed at exploring attitudes towards research, use of a traditional Hawaiian practice for family discussion, and study promotion. Social marketing theory guided the development of discussion questions and a survey. Through purposive sampling, 30 women from medically underserved communities were recruited. Content analysis was used to identify major discussion themes. Findings indicate that lack of informational access may be a major barrier to participation. Study information disseminated through community channels with targeted outreach to social and religious organizations, promotion through face-to-face contact with researchers, and culturally tailored messages directed to families were preferred. Community oriented strategies based on linkages with organizational networks may increase participation. *Key Words:* Native Hawaiian, clinical trials, health disparity

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Background and literature review

Native Hawaiian women experience unequal suffering and death from cancer. Incidence, prevalence, and mortality rates for cancer (all sites) are higher than for women of any other ethnic group in Hawai'i and higher than for most other groups in the United States¹⁻³. Native Hawaiian women as a group, also have a higher incidence of cancers diagnosed at advanced stages when treatment options are more limited and survival outcomes compromised¹. The Cancer Awareness Strategic Plan for Native Hawaiian Communities⁴ underscores the need for evidence-based research to address current disparities and calls for culturally grounded intervention research including those related to improving patient's quality of life.

Na Lei Pulama (NLP) or "cherish our beloved ones," was a feasibility study testing an adaptation of *ho'oponopono*, an indigenous Hawaiian healing practice, to mitigate the negative psychosocial effects of cancer among Native Hawaiian female patients and their families. *Ho'oponopono* means "to set things right" and is a familial process involving discus-

sion and spirituality⁵. In this feasibility study, a structured intervention based on *ho'oponopono* as taught by Pukui⁵ and her students⁶ was developed through expert consensus⁷. Community practitioners were trained to deliver the NLP intervention as specified in the research protocols. To test this approach, NLP tried to recruit Native Hawaiian women and their families to participate in NLP or a control program to see which was better at improving the quality of life after a cancer diagnosis. The NLP adaptation of *ho'oponopono* is documented elsewhere⁷.

Promotional strategies proven effective in other studies^{8,9} such as media campaigns, mass mailings, and presentations to providers and patient groups yielded disappointing results in accrual to NLP. To address this shortfall in participation NLP researchers conducted focus groups, as informed by the minority recruitment and health communications literature.

The capacity to recruit study participants is crucial to intervention research and a challenge to investigators, regardless of study population. However, recruitment of minorities and women may be especially difficult due to cultural norms, negative perceptions of research, and structural barriers that complicate research access and participation^{10,11}. Targeted mass mailings and media presentations are among those approaches identified as most effective in recruitment of women and minorities to cancer research¹¹. Dialogue between researchers and potential participants and promotion through community networks are reported as "best practices^{10,11}".

Native Hawaiian participation in research is associated with distrust of conventionally conducted research and specific barriers may include: lack of tangible benefits to community residents, failure to integrate intervention programs with established social systems influential in maintaining behavioral norms, and past research experiences that disregarded participant need for empowerment^{2,12}.

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These findings underscore the importance of community involvement across all research phases and speak to the need for promotions that are acceptable to targeted communities.

Social marketing theory is focused on the process of increasing acceptability of an idea or practice in a targeted group and is widely used in cancer and other health-related promotions, including those specific to study recruitment^{13,14}. While there are several models currently used in health communications, most emphasize three common elements: the source, messenger or origin of the information transmitted; the message or content of what is being communicated; and the channel or medium used to disseminate communication¹⁴. Using approaches that attend to these common elements, promotional efforts may be further enhanced through cultural tailoring that specifically addresses the needs and cultural preferences of the targeted community^{13,14}.

According to the Institute of Medicine (2002)¹⁵, effective health promotions optimally incorporate an understanding of the sociocultural context in which decision-making and behavioral change occur; failure to incorporate such understanding in promotional communications may compromise efficacy. Strongly recommended is the use of culturally specific symbols, metaphors, and language in promotion and recruitment. By extension, promotional print materials for Native Hawaiians might incorporate images and linguistic terms that convey spiritual harmony and affiliation with family and community networks^{12,16}.

Guided by the empirical literature on social marketing and minority recruitment, NLP researchers conducted focus groups to: explore Native Hawaiian women's attitudes toward research participation, assess the relevance of *ho'oponopono* in cancer care, and identify salient issues and approaches for developing future promotional strategies.

Methods

A brief survey and a semi-structured schedule of discussion questions were developed for focus groups held in February 2004. After obtaining approval from the institutional review boards of the Native Hawaiian Health Care Systems and the University of Hawai'i, purposive theoretical sampling methods¹⁷ guided recruitment to focus groups. To reach Native Hawaiian women from medically underserved communities, three established groups (two health and fitness groups and one residents' association) were approached. The final sample was composed of 30 women

from both urban and rural areas of O'ahu island. The majority (28/30) were elderly (mean age = 61 years, s.d. = 10.65), of Hawaiian ancestry (28/30), lived in medically underserved communities outside of the city of Honolulu (20/30), and had completed high school (26/30).

Focus groups were convened after regularly scheduled organizational meetings and facilitated by a Native Hawaiian, female social worker (MSW) trained in the focus group protocol, but not directly involved in the NLP intervention. The facilitator secured informed consent, administered the survey, distributed sample promotional materials for review, and elicited discussion using the semi-structured schedule of questions. At the conclusion of each group, participants were thanked and offered a \$10 voucher for use at a local sundry store. Community outreach workers from Ke Ola Mamo—the Native Hawaiian Health Care System on O'ahu—coordinated logistical arrangements and provided on-site assistance. Sessions were about one hour in length and audio taped for subsequent verbatim transcription. De-briefings, held immediately after each session involved the facilitator, outreach workers, and a research team member. Impressions of major themes were noted and considered in the analysis of transcripts.

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The seven-item questionnaire elicited socio-demographic information (i.e., Native Hawaiian ancestry, place of residence, educational level, age) and experience with cancer and *ho'oponopono* (i.e., cancer diagnosis of participant or someone close to them, acceptability of talking about cancer, acceptability of *ho'oponopono* in cancer care). Discussion questions focused on eliciting reactions to the source, message, and channel of NLP's promotional efforts. Participants' experiences with cancer, *ho'oponopono*, and research were explored and suggestions sought to inform future recruitment.

Materials reviewed included: a public service announcement (PSA) about NLP and three other cancer support studies, a newspaper article that featured NLP and another Native Hawaiian cancer intervention study, and a tri-fold brochure specific to NLP. The PSA provided a one-sentence description about each of the four studies and directed inquiries to a central telephone line. Intended for use with a general audience of female cancer patients, the PSA was designed to be culturally neutral and avoided use of Hawaiian terms and cultural symbols. The article was from the newspaper of a large Native Hawaiian organization with statewide distribution. It included information about Native Hawaiian women and cancer, bulleted points about NLP, and selected quotations and a photograph of the PI. The NLP

tri-fold offered bulleted details about the purpose of the study, participant benefits, eligibility criteria, and contact information. Vibrant colored images of flower garlands (*lei*) and Polynesian women in discussion were used.

The research team used content analysis¹⁷ to identify major themes. Each team member reviewed transcripts for thematic content and developed a preliminary coding system. Preliminary codes were discussed with a final coding system developed through consensus. To ensure accuracy of interpretation, all findings were reviewed by the group facilitator and a staff member from the NCI's Cancer Information Service of Hawai'i; the latter was not Hawaiian, but was experienced in cancer promotions with Native Hawaiians.

Findings

Relevance of *Ho'oponopono*

The majority (29/30) viewed *ho'oponopono* as a relevant process for use in cancer care. *Ho'oponopono* was associated with values central to traditional Hawaiian culture—namely, the emphasis on the individual in the context of the family and the inextricable relationship of spirituality to relational harmony and physical wellness. Participants explained that spirituality was a source of strength and optimism in adversity and thus, offered a psychologically safe context for discussing concerns, resolving conflicts that might pose barriers to support of the sick family member, and reaching agreement on how to proceed with health concerns and daily responsibilities. Most participants (23/29) had experienced cancer as either a patient or the loved one of a patient. They acknowledged that talking about cancer was difficult, but important as a means for unifying family members in providing support to each other.

“Getting family involved is part of healing because whatever happens, you always need your family.”

“When there's something hard to talk about like cancer, the spirituality in *ho'oponopono* gives strength to go on.”

Attitudes towards research

Most participants (25/30) indicated that cancer research specific to Native Hawaiians is needed. Notably, none of them had heard of NLP prior to the focus group discussions and the need for information about NLP and other Native Hawaiian cancer research was emphasized.

“We need to know about Native Hawaiians and cancer. Most of my family have died from this disease.”

“It's important to get involved, it could help Hawaiians.”

Women recognized the need for involvement, but several (5/30) raised concerns about research participation in general and/or about NLP in particular. Negative perceptions about research included: reluctance about having one's life put up for possible negative evaluation, the short-term nature of pilot interventions, and the failure of past research projects to report study results to community members.

“I see free services and think there's a catch. Somebody's going to study me.”

Acceptance of the *ho'oponopono* leader (*haku*) was the most frequently expressed concern specific to NLP participation (4/30). NLP involves the use of a *ho'oponopono* leader trained in study protocols; thus, the discussion leader is likely to be an outsider to participating families. Focus groups felt that an outsider might be unfamiliar with relevant family history.

“Cancer is a personal matter. If a stranger leads *ho'oponopono*, it might not be 100% acceptable right away. It really depends on that person.”

Although viewed as potentially problematic, group members did not necessarily see this as a barrier to participation. It was clarified that “much depended on the leader” who was ideally sincere, competent, and patient. If these conditions were met, participants agreed that the objective perspective of a leader who was not part of the family system could be helpful.

“If the person is humble, if their ‘insides’ are good and words and actions tell the same story then the family will probably accept them.”

Two participants were concerned with the time-consuming nature of *ho'oponopono* and explained that contemporary families are busy with multiple responsibilities, many of which are outside of the home. They wondered about the difficulty of coordinating a time when all members could be convened.

Having an opportunity to discuss concerns through focus group discussions seemed helpful to participants. After reviewing and discussing NLP's print materials, almost all (27/30) indicated that they were inclined to call the project for more information if a family member was diagnosed with cancer.

Messengers

Project personnel (i.e., PI, *ho'oponopono* leader, others involved in intervention delivery) were viewed as the most

important source of study information and all 30 participants felt that contact with these personnel was important. Through their review of project materials, specifically the NLP tri-fold brochure and newspaper article, participants learned that the study was led by a Native Hawaiian investigator who had both professional and personal experience in cancer. This information predisposed them to regard NLP in a positive light. However, most participants felt that print information was not sufficient to motivate study participation and that discussion about the research prior to enrollment was necessary.

“Brochures are good to read, but project staff needs to talk to families, too.”

Native Hawaiian cancer survivors, especially those who had successfully completed the intervention were also viewed as potential messengers. Participants speculated that study enrollment might be facilitated by the personal testimony of survivor role models.

Channels

The majority (28/30) suggested that study information should be disseminated through community-based organizations such as senior citizen groups, churches, social clubs, and neighborhood associations. One participant suggested that promotional efforts needed to “go where people are.”

The influential nature of friendship networks within community organizations was highlighted. Women in such networks were described as having similar cultural and age-related experiences, and these similarities served as the basis for fostering enduring relationships. Valued as sources of emotional support and information, these friendship networks were viewed as influential in decision-making and help-seeking during adverse times.

“There’s a connection in this group. I can open up and be understood. This is one of the first places I’d come for help.”

Other promotional channels identified by focus group members, included: researchers’ participation in community events, referral by health care providers and community health outreach workers, strategic posting of NLP materials (e.g., in waiting areas of clinics and radiology units, community, residential, and church bulletin boards) and use of Native Hawaiian and community media.

Messages

Interest was piqued by messages about the impact of cancer in the Native Hawaiian population including the ways in which the cancer experience may affect family well-being. Such messages led to the desire for study information. Most (28/30) stated that information about the study should include: the nature of participation, eligibility criteria, and potential benefits. Participants agreed that the NLP flyer and newspaper article offered sufficient information.

The majority (25/30) preferred the format of the NLP tri-fold brochure and explained that they were drawn to the brightly colored images of *lei* (flower garlands) and women. Large print and bulleted presentation of salient information were appreciated. A minority (5/30) preferred the newspaper article and specifically referenced the importance of including personal experiences with cancer. Personal experiences or stories were described as the “hook” and offered “emotional understanding” and “connection” to the purpose of the project—all of which were perceived as motivating participation.

“I saw the connection to the family—the *piko* [umbilical cord].”

Limitations

There are a number of study limitations. First, group discussion focused on issues related to promotion of NLP, a culturally grounded intervention; thus, findings cannot be generalized to use in other studies. Second, a non-patient sample was used and findings may not reflect the views of cancer patients for whom NLP is intended. Third, focus group responses are subject to social desirability bias, and findings may not reflect the opinions of all members. The influence of social desirability may be particularly powerful in Native Hawaiian groups because traditional culture places

Table 1. Considerations for increasing participation	
Promotion Messengers	<ul style="list-style-type: none"> • Research team (principal investigator, practitioners delivering intervention) • Cancer survivors • Face-to-face contact and discussion preferred
Dissemination Channels	<ul style="list-style-type: none"> • Community-based social & religious organizations • Community events • Health clinics • Broadcast and print media • Ethnic-specific and community media preferred • Culturally tailored print materials preferred
Messages	<ul style="list-style-type: none"> • Relevance to individuals, families, communities • Study information (what participation involves) • Personal stories about cancer experience and study benefits

high value on harmonious relationships, and strong differences of opinion may not surface in time-limited discussions such as those conducted. Fourth, the very nature of focus group methodology advantages the opinion of those most comfortable speaking in groups and this likely influenced the nature and extent of information disclosed, as well as any consensus reached. Finally, group members were recruited through their association with social organizations, and sampling methods may have biased the study in the direction of more participatory community members who might also be more likely to participate in research. Despite these limitations, small group discussions seemed to provide a comfortable environment and an acceptable style allowing for frank discussion. Notwithstanding cautions, the comments received from focus groups hold several implications for developing promotional strategies to increase research participation.

Discussion

Knowing what to include in a promotional message, who should deliver it, and how best to disseminate it are central issues for influencing participation. Table 1 displays a summary of considerations by issue area based on insights from Native Hawaiian women.

Attention to key relationships is a common theme across issue areas. Indicated is the need for community oriented strategies that consider the relationship between researchers and communities, between women and family members, and between women and friends—the latter of which may be embedded in the networks of social and religious organizations. Native Hawaiian women emphasized the need for face-to-face contact with research team members and suggested that researchers are important messengers for study promotion. Family-oriented messages and when appropriate, inclusion of family members in promotional efforts were also suggested. Community venues were viewed as channels for reaching individuals, families, and friends. The need to know researchers and the need for researchers to know families and communities were frequently articulated. By extension, use of community channels presents an opportunity for this bi-directional learning to occur.

Strongly indicated is the need to disseminate study information through established social and religious organizations. Native Hawaiian women told us that friendship networks within organizations are a vital source of emotional and informational support and thus, spoke to the potential of increasing research participation through education and discussion with women in such networks.

Considerations derived from our focus groups are consistent with findings from the landmark Wai'anae Cancer Study¹⁸ and studies from other native and ethnic minority communities^{10, 19} that highlight the value of community-oriented and relationally-based strategies in effective re-

cruitment. Without equivocation, participant recruitment is crucial to intervention research that ultimately advances effective practices for enhancing patient quality of life. In the development of culturally tailored interventions, researchers also need to incorporate culturally appropriate and community-relevant methods of study promotion. Strongly indicated is the need for future research that systematically evaluates the effectiveness of community-based approaches with Native Hawaiians and other medically underserved groups.

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If one pays attention to an unattractive girl,
it is because a woman's face is not her only virtue.

Chuukese proverb