Published in final edited form as:
Prog Community Health Partnersh. 2008 ; 2(4): 291–299. doi:10.1353/cpr.0.0040.

Cancer Assessment Methodology in a Native Hawaiian Community

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Abstract

Background—Limited data have been collected on cancer in Native Hawaiian communities, although Native Hawaiians tend to have higher cancer mortality rates than other ethnic groups in Hawai`i.

Objectives—We sought to describe the community-based participatory research (CBPR) process used to deliver a culturally tailored protocol, combining traditional Native Hawaiian practices and random sampling methods, to determine cancer screening practices and program preferences of residents of a Hawaiian Homes (HH) community.

Methods—Following a culturally tailored protocol, we at tempt ed to survey half of the 644 households in the Waimānalo Hawaiian Homes Community (WHHC). Pairs of Native Hawaiian college students performed the majority of data collection; a community member joined them if avail able. Visits to the selected homes were tracked and participation rates estimated. Additional information on this method ology emerged from discussions between researchers and community members.

Results—Of the 449 households accessed, 187 (42%) completed the survey, with an average of two visits per household. Individuals at 63 (14%) households refused outright. The remaining 199 (44%) homes were visited up to five times, but produced no response. Although some homes were vacant, often it appeared that residents were home but unresponsive. Our sampling procedure (targeting every other house and requiring accrual of 75 individuals in each of four age–gender groups) reduced participation.

Conclusions—The use of CBPR built capacity for all partners by engaging them in all levels of research. The results, however, suggest the need for a more inclusive sampling strategy and the continued use of CBPR.

Keywords

Community-based participatory research; needs assessment; health care quality, access, and evaluation; Pacific Islands; health disparities

Studies have documented the existence of significant health disparities in the United States, especially among its indigenous peoples.[1–3] Research shows that both lower socioeconomic status and minority race/ethnicity are associated with poorer health and lower health care utilization.[4,5] In Hawai`i's ethnically diverse community, people with Native Hawaiian ancestry makeup 22% of the population.[6] When compared with other ethnic groups in the state, Native Hawaiians report lower average incomes, lower life expectancy, and higher cancer mortality.[7,8] Native Hawaiians tend to be diagnosed with late-stage cancers and have lower screening rates than other ethnic groups in Hawai`i, contributing to their higher cancer mortality rates.[9]

Accessing data about minority health knowledge, attitudes, and practices is limited for several reasons.[10] First, it is difficult to obtain sufficient data on minority groups using national or statewide surveys owing to the small numbers of individuals in certain populations. The U.S. Census for example, does not provide information for populations of less than 65,000.[11] Second, standard survey tools and methods often lack the cultural sensitivity necessary for collecting data about specific populations.[12,13] For example, survey data often are collected by mail or phone, and low-income, minority residents may lack a permanent address and/or phone. CBPR strives to overcome some of the barriers associated with standard data collection methods by involving community members in the planning and conduct of surveys, increasing their level of representation and heightening the awareness of their issues and concerns.[14,15] CBPR is especially relevant in health care because “understanding the quality of life and its cultural patterning for the community is essential for planning and delivering appropriate health care.”[16]

The effectiveness and sustainability of interventions depend largely on levels of community involvement, therefore, the community should play an essential role in research.[17] In 2006, Ke Ola Mamo (KOM), the Native Hawaiian Health Care System (NHHCS) providing access and primary care services on O`ahu, was funded to conduct a cancer needs assessment that combined traditional Native Hawaiian information-gathering protocol with standard sampling methods in the WHHC. This paper describes the partnerships, method, and process we, as a community-based organization, used to engage WHHC residents and build community capacity. The findings from this project will guide the development of programs to reduce cancer health disparities in Native Hawaiians.

METHODS

Partnerships

To facilitate this study, a partnership was formed between four organizations—KOM, the Waimānalo Hawaiian Homes Association (WHHA), `Imi Hale – Native Hawaiian Cancer Network, and the John A. Burns School of Medicine (JABSOM) at the University of Hawai`i. Previously established relationships existed among the partners. KOM received the funding to conduct the project and was home to the Principal Investigator (DP) and Research Assistant (AS) who coordinated the study. DP worked with HH community members and the Department of Hawaiian Home Lands to develop the grant proposal. The President of the WHHA and a resident of the WHHC, Paul Richards, showed the most interest and became a co-investigator on the project to ensure community involvement, comfort, and participation in the research process. The WHHA was established in 1938 by the first residents of the WHHC to promote the welfare of its members.[18]

`Imi Hale is 1 of 25 Community Network Programs funded by the National Cancer Institute to reduce cancer health disparities by increasing cancer research and programming by and for Native Hawaiians. They provided technical support, mentorship, and assigned college-level Native Hawaiian in terns as data collectors. KOM and `Imi Hale have a history of collaboration, and DP and AS are members of `Imi Hale'sindigenous researcher program. The final partnership was formed with a faculty member at the Native Hawaiian Center for Excellence at JABSOM, who assigned first-year Native Hawaiian medical students to assist with data collection.

Community Description

The Hawaiian Homes Commission Act of 1920 and the subsequent establishment of the Department of Hawaiian Home Lands in 1921 were sanctioned to increase access to land and housing for Native Hawaiians by providing 99-year land leases. HH communities are not "reservations," but certain qualifications (50% Native Hawaiian blood quantum) must be met to obtain a lease.[19] Approximately 23,000 Native Hawaiians live in HH communities.20

The WHHC is 1 of 13 HH communities on O`ahu and encompasses 644 households.[21] Situated along the windward coast, this rural community has limited access to health resources. Waimānalo Health Center, the community health center serving Waimānalo and other windward O`ahu communities, was established in 1992.[22] Our focus on HH residents, who have higher Native Hawaiian blood quantum than other Native Hawaiians living in Hawai`i, is significant because higher blood quantum has been associated with increased morbidity and lower socioeconomic status.[23,24]

Institutional Review Board Approval

When designing the study, the partners considered the three main survey methods, namely, mail, telephone, and face-to-face interviews. The partners decided to conduct a door-to-door survey because of the Native Hawaiian preference for face-to-face interactions.[25,26] Previous surveys of HH communities obtained high response rates using face-to-face methodologies, validating their effectiveness and appropriateness.[27,28] Although telephone and mail surveys require fewer resources, they would not have been culturally appropriate or feasible for this community. The research mentors at `Imi Hale contributed to the methodology by working with DP to develop the random sampling method.

To further ensure cultural competency and community involvement, the partners presented the preliminary study design at two Combined Council meetings. The Combined Council, developed by `Imi Hale to serve as their advisory board, consists of a Community Council, Scientific Council, and Steering Committee composed of lay community members, cancer survivors, cultural experts, health professionals, Native Hawaiian researchers, and individuals from business, media, and Native Hawaiian organizations. Quarterly meetings are held for people associated with the Native Hawaiian community to present, discuss, and receive feedback on their projects. The traditional Native Hawaiian emphasis on oral transmission of knowledge reflects the importance of orally presenting a project to the community and asking for their approval. Additionally, many cultural practices are passed down orally within families, making them difficult for research ers to access without good community relationships.25,[26] A cultural expert at a Combined Council meeting shared the traditional way to seek knowledge, keeping the mountains to the right, allowing us to tailor our methodology (Smith A. Kumu Hula and `Imi Hale Community Advisor. Personal communication, October 2006).[29] In compliance with Combined Council concerns regarding cultural appropriateness and scientific rigor, the following protocol was adopted:

> Choose the street that is perpendicular to *mauka* (toward the mountains) or closest to *mauka*. Select the second house on the right, keeping the mountain on your right. Continue walking on the right-hand side of the street, keeping the houses on your right and the road on your left. Skip one house, and select the next. If you reach the end of the street, turn right at the next intersection. If there are no more dwellings visible (e.g., you reach a dead end or enter a rural or commercial area), cross the road and come back along the opposite side. Continue interviewing at every second household. If you go right around the block, and come back to the dwelling you started from, cross the road, turn to face the opposite direction, and continue your route on the other side of the road, keeping the mountain on your right (Smith A. Kumu Hula and `Imi Hale Community Advisor. Personal communication, October 2006).[29,30]

Upon completion of the study design and assessment tool, KOM presented its proposal to the NHHCS Institutional Review Board (IRB) as well as the University of Hawai`i's Committee on Human Subjects Research for review. The NHHCS IRB committee is composed of lay community members (majority) and established academic researchers from the Native Hawaiian community, many of whom attend Combined Council meetings. Given the survey design and inclusion of the larger Native Hawaiian community in the design process, both IRB approvals were expedited.

Assessment Tool

The 57-item assessment tool, entitled “Native Hawaiian Health Access and Utilization Survey,” included items from various local and national sources. `Imi Hale researchers helped KOM to incorporate relevant questions from nationally validated surveys. The tool contained questions from the KOM intake form about health care utilization and coverage. Demographic items included age, gender, education level, employment, income, and number of household members. Cancer knowledge items included true or false questions about the role of family history in cancer risk and the need for and timing of screening. Cancer attitude items used a Likert scale to assess perceived importance and usefulness of screening and fears about screening pain or findings. Also included were items from the nationally validated Behavioral Risk Factor Surveillance Survey, used by the state of Hawai`i Department of Health, about lifestyle practices (e.g., smoking, fruit and vegetable consumption, and physical activity) and cancer screening behaviors. Another section asked about preferences for community-based cancer education, for example, through health fairs, free screening events, and lectures. Two open-ended items solicited information on past health events that have been successful and ideas for future health events. Similar questions were asked in previous HH research.[27,28] All of the partners reviewed and provided feedback on the survey.

The WHHA co-investigator facilitated access to a segment of the Native Hawaiian kūpuna (elder) population in the WHHC for pretesting of the survey during focus groups. The partners decided on pretesting with kūpuna because they are respected and accepted as a source of wisdom.[31] This pretesting prompted the development of answer cards to help participants with multiple choice questions and the modification of certain questions. Participants in the pretesting also commented on the cultural appropriateness of the survey and gave their approval. Traditionally, questions about health history or family relationships are considered “more than rude,” emphasizing the importance of pretesting to ensure questions would not be offensive to WHHC residents.31

Mapping and Selection

In addition to being culturally appropriate, the door-to-door surveying method allowed KOM to provide on-the-spot help and information about accessing health insurance and services to individuals. Local and national studies have also shown high response rates in minority populations using this methodology.[16,27,28,32–34] We attempted to survey approximately half of the 644 households in the WHHC to ensure a minimum of 75 individuals in each of four age–gender groups—men age 25 to 49, men 50 and older, women age 25 to 49, and women 50 and older. We used the Hawai`i State Tax Map Key (TMK) to visualize the community and create a mailing list.

Before the start of data collection, a letter informing the community about the project and partners involved that also encouraged participation was mailed to all homes in the WHHC. The President of the WHHA delivered the same message on a local television station and to members of the Waimānalo community board. Native Hawaiian sensitivity to invasive questions mandated that we advertise the relevance of our assessment.[31]

Using the TMK maps, approximately 400 homes were preselected and divided into 10 clusters of 40 homes. In accordance with the protocol, we chose a street intersection as the start point for each cluster. Owing to the complicated nature of maintaining the protocol given the geographic layout, interview pairs received an ordered list of preselected homes with the street address, house code (for confidentiality), and space for comments. This system reduced confusion for the interviewers and allowed for visit tracking. The ordering of the homes helped interviewers to keep the mountains to the right and maintain protocol. Oversampling accounted for vacant lots and to help meet age–gender quota requirements. Additionally, unselected homes were added if residents ex pressed a strong desire to surveyors to participate.

Data collection occurred for 6 months, from March 2007 to August 2007, and data collection sessions were scheduled in 2-hour time slots—10:00 AM to 12:00 PM and 4:00 PM to 6:00 PM on weekdays. These times were chosen, after discussion with WHHA members, as the optimal times for residents to be at home. Approximately 20 to 30 homes were visited during each 2-hour data collection session and, on average, two or three surveys were completed per session.

Survey Administration

Most surveyors were of Native Hawaiian ancestry and interested in health care. All received extensive training from members of the KOM research team on the survey tool and data collection protocol. Interviewing was always done in pairs. WHHC members joined the pairs when available and were compensated for their time. This person always proved helpful in gaining access to the dwellings and increasing response rates, but did not conduct interviews.

The interviewer training demonstrated adherence to cultural practices. Surveyors were required to first observe and listen to an experienced interviewer conduct the interview, then were supervised in their first few interviews. Traditionally, Native Hawaiians learned through observation, listening, and practicing.[35] To ensure cultural sensitivity when approaching homes, WHHA members instructed interviewers to call to residents from outside of property boundaries and identify themselves. If residents responded, interviewers then explained the survey purpose and process. In Native Hawaiian culture, asking personal questions is more appropriate if reasons for the questions are understood and deemed acceptable.[31]

Interview pairs received packets containing a copy of the initial letter sent to the WHHC, consent form, survey, informational health brochures (on cancer, diabetes, and KOM services), the WHHA brochure, a request for services and/or results form, and a $10 gift card for a local supermarket to thank the householder for his or her participation.

If a resident was home and willing to participate, interviewers obtained informed consent and screened the resident to ensure eligibility (over 25 years old and a resident of the WHHC). If the resident did not meet the eligibility requirements and no eligible resident was available at that time, the interviewer gave them informational brochures and returned at a later date to try to interview an eligible resident. If the resident met the requirements, one interviewer conducted the survey while the other observed to ensure quality control. Upon completion of the survey, participants were asked if they would like to receive KOM services and/or the results of the survey. Participants were given informational health brochures and the $10 gift card. Although not initially in our plan, multiple residents of the same household were allowed to be interviewed because it was perceived as culturally inappropriate to refuse interested residents.

Post Survey

After each data collection session, interviewers discussed observations and comments with AS. The tracking sheets were also reviewed to monitor response rates and determine homes to be revisited. If no residents were present in the selected house, interviewers continued to visit the dwelling up to five times in an attempt to reach the resident.

Data Analysis

Survey data were managed in SPSS version 15.0, which was used to produce frequencies. Tracking sheets were entered and participation rates calculated. Qualitative analysis was performed on observations and comments of the surveyors, and the two open-ended survey questions. `Imi Hale provided training on SPSS software and helped with data analysis.

Dissemination

In October 2007, the survey findings were disseminated to the WHHC through focus groups held in WHHA facilities. During the focus groups, members of the research team presented an overview of the findings and asked community members for feedback. A preliminary report was mailed to interested community members in January 2008. Information about the survey findings was also disseminated to the community at the WHHA board meeting, in the local Waimānalo newspaper, and at WHHC events. The research team presented the study at the April 2008 Combined Council meeting. Findings from the survey itself are the subject of a future paper.

RESULTS

Survey Participation

After 6 months of data collection, 449 homes had been approached (Table 1). Surveys were completed in 187 homes, representing approximately one third of the 644 households in the WHHC. Among these homes, 45 individuals requested and received follow-up assistance from KOM in obtaining health insurance and/or accessing health or dental care services for themselves or family members.

Individuals in 63 homes (14%) declined to participate. Nine homes (2%) were vacant or inaccessible. For the remaining 190 homes (42%), there was no answer to our knock or call, even after the requisite five visits to the home (although in many homes we heard noises inside the house, suggesting that residents were avoiding surveyors).

We calculated participation rates in several ways to ensure an accurate representation of the sample (Table 1). Response rates ranged from 42% to 75%, which is comparable with similar surveys.[34,36,37] Because of the multiple visits required to obtain a response, we also calculated a visits-per-completed-survey rate as a measure of efficiency. On average, completed surveys required two visits, refusals required one visit, vacant/inaccessible required one visit, and no response were five visits. Thus, completed surveys required 7.5 visits (Table 1). The completion of 187 surveys took 16 interviewers 6 months and more than 500 person-hours to complete. Given limitations in funding and the inconsistency of WHHC member availability, data collection was dependent on voluntary contributions of time by surveyors, so turnover was high.

The difficulties encountered with participation hindered our ability to meet the age-gender quotas. Two thirds of our respondents (n = 124) were female, and 63% were age 50 or older (Table 2). Male participation was low for both age groups, only 28 (15%) participants were males age 25 to 49 and only 35 (19%) participants were males age 50 and above.

Qualitative Results

The use of Native Hawaiian data collectors from `Imi Hale and JABSOM supported the development of indigenous researchers, and the mentorship provided by `Imi Hale staff increased KOM's research capacity. Surveyors responded positively to working in the community and felt that the project built their professional skills and supported their interest in health. Community members also responded positively to seeing Native Hawaiian researchers in their community. The involvement of community members in the data collection process built trust and strengthened the case for future collaborations. The low participation rates and difficulty of following the information-gathering protocol, however, frustrated surveyors.

Methodology

The implementation of this methodology had both benefits and limitations. Although the incorporation of traditional practices complicated the data collection process, it engaged the Native Hawaiian community and strengthened the cultural knowledge of the researchers. The door-to-door method allowed us to access a portion of the community that might be less inclined to participate in community events like focus groups. KOM was also able to provide direct assistance to WHHC members, raising KOM visibility and building upon existing strengths and resources within the community. Additionally, going into the community and conducting face-to-face interviews provided valuable experience for the interviewers and useful anecdotal evidence about WHHC characteristics.

The limitations associated with this methodology, however, cannot be overlooked. The exclusion of every second home could be easily misinterpreted by WHHC members and hindered recruitment efforts. Given the size and relationships in the community, it would have been more appropriate to visit every household. For example, some interviewees volunteered to contact their neighbors for interviews. Although this method of neighbor introductions was very effective, it made it difficult to follow our protocol. Previous research has shown that neighbor-to-neighbor interaction produces good response rates and our experience supports this finding.[38]

Additionally, the quota system of sampling set inappropriate exclusion criteria and proved difficult to meet given the low participation rate. Cultural sensitivity mandated that all interested residents have the opportunity to be interviewed, thereby skewing the age–gender quotas. The interviewers observed that men often deferred to their wives once they understood it was a health survey. Traditionally, Native Hawaiian women take responsibility for family health.[39] The low participation rates of residents between 25 and 49 years old could imply less interest in community projects and reflect the competing demands of work and family. The majority of our respondents were older than 50 because they were more likely to be home and more open to participation in the survey. The quota system, therefore, proved unrealistic and hindered data collection.

The physical geography of the WHHC made data collection an arduous and time-consuming task that significantly complicated the survey process. The Ko`olau mountain range surrounds the WHHC on three sides, making it difficult to follow the “mountains on the right” rule. Additionally, the roadways in the community were not conducive to maintaining the protocol. To overcome the difficulties associated with the protocol, additional measures (preselection of homes and the creation of a mapping system) were necessary.

Survey Tool

The optimal survey time seemed to be 10 minutes. Survey times, however, were independently related to the time spent at a respondent's home because surveyors needed to “talk story” and build a trusting relationship with the interviewee. Shortening the survey time, therefore, did not necessarily lead to less time spent at each house and more homes visited in a data collection session.

The majority of the questions in the assessment tool regarding health care access, lifestyle, and demographics were easy for respondents to answer. Even with extensive pretesting, however, some of the questions required interviewers to reword statements and provide additional information. Many of the interviewees had difficulty using the Likert scale to agree or disagree with statements. The statements themselves also proved difficult for interviewees, particularly the kūpuna, to understand.

Bias due to social desirability could have affected the data, especially given the extent of interviewer prompting. Previous studies have shown the effects of social desirability in face-to-face interviews.[32,38] In this study, social desirability could have affected the following areas: the overreporting of screening behaviors, feelings toward interventions, and acquiescence when unable to understand the question.

DISCUSSION

CBPR Aspects

Historically, research has been conducted and controlled by academia and institutions, disenfranchising community. Three central tenets of CBPR—creation of a co-learning environment, shared decision making, and mutual ownership—represent a shift in this paradim.[15,40] The active inclusion of community in this project from design to dissemination reflects the implementation of CBPR principals among the partner organizations and the greater Native Hawaiian community. Institutional support of a community-based and -driven project is especially important for empowering commu nities and facilitating change.

The established relationships between partner organizations and their involvement in all stages of the project ensured a sharing of knowledge and co-learning environment. The inclusion of the Native Hawaiian community in the research design further demonstrated a co-learning environment and encouraged community ownership of the project. Although the inclusion of the larger community complicated the research design, community knowledge enabled the major innovation of our methodology (the combination of traditional protocol with standard survey methods). The use of traditional protocol and training practices supported the reclaiming of Native Hawaiian identity after centuries of acculturation.

Future Direction

This project strengthened the case for future CBPR endeavors; it would not have been possible without the resources and relationships provided by our partner organizations. Given the difficulties of following our protocol, however, a simpler, more inclusive, face-to-face data collection protocol would be appropriate and might increase participation. Practical concerns, such as community geography, should be considered before utilizing traditional practices. The limited studies conducted locally in HH communities chose a smaller sample size (100 residents), decreasing the resource burden, and allowing them to spend more time building community relationships, resulting in high response rates.[27,]28 We built trust by advertising and partnering with the WHHA. Establishing trust, however, between individual residents and researchers may be necessary to increase participation rates. Using community members as the primary interviewer may increase participation, although interviewees may be hesitant to discuss health-related issues with neighbors. A 1977 survey of two HH communities achieved a 91% response rate by building individual relationships and using a door-to-door request for a self-completion survey.28 In addition to being culturally appropriate, this method retains the value of increased organization visibility and immediate access to assistance and services.

Recent research suggests the use of Qualitative Description focus groups as a method for “assessing, developing and refining clinical interventions with vulnerable populations.”[41] Qualitative Description is a more holistic approach to data collection and eliminates the need for high-level data interpretation, allowing findings to be based in cultural contexts that often defy standard data collection methods. Generally focus groups also require fewer resources than door-to-door surveying.

In conclusion, cultural tailoring, community engagement, and establishing trust between researchers and community members ensure high participation rates, culturally appropriate practices, and quality data. Community empowerment requires their active involvement in a project from start to finish. Community ownership and involvement in a research project contributes to the efficacy of the study, increasing the data available on vulnerable populations and promoting the reduction of health disparities.

Acknowledgments

This study was funded by the National Cancer Institute grant #3U01CA114630-02S2. The authors would like to thank Paul Richards of the Waimānalo Hawaiian Homes Association, Dr. Kathryn L. Braun of `Imi Hale, Dr. Shannon Hirose-Wong and first-year medical students in the John A. Burns School of Medicine, the Waimānalo Hawaiian Homes community, and Ke Ola Mamo for their assistance with this study.

This study was funded by the National Cancer Institute grant #3U01CA114630.

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Table 1

Response Rates, Cancer Assessment Methodology Study, 2007

Response	**Number of Homes**[*]	**Percentage of Total Homes Visited**
Completed	187	41.6
Refused	63	14.0
No Response	190	42.3
Vacant or Inaccessible	9	2.0
Completion Response Rate[†]	187/(449 – 190 – 9)	75.0
Participation Rate[‡]	187/449	42.0
Visits Per Completed Survey[§]	(187 × 2) + (63 × 1) + (9 × 1) + (190 × 5)/187	7.5

[*] Total number of homes visited = 449.

[†] Completion response rate = Completed surveys/(Total homes accessed – No response – Other).

[‡] Participation rate = Completed surveys/Total homes accessed.

[§] Visits per completed survey = (Completed surveys × 2 visits) + (Refused × 1 visit) + (Other × 1 visit) + (No response × 5 visits)/Completed surveys.

Table 2

Demographics of Survey Respondents by Age and Gender, Cancer Assessment Methodology Study, 2007

Gender	Age 25–49 Yrs	Age ≥50 Yrs	Total
Male	28	35	63
Female	41	83	124
Total	69	118	187