

Cultural Considerations for Conducting the Health Information National Trends Survey with Micronesian Communities: Lessons from a Qualitative Study

Kevin Cassel DrPH; Hye-ryeon Lee PhD; Lilnabeth P. Somera PhD; Grazyna Badowski PhD; and Megan Kiyomi Inada Hagiwara DrPH

Abstract

A critical barrier to addressing health disparities among minorities is the lack of data, particularly on Pacific Islanders. Typically, national health surveillance systems do not have the resources to ensure proper representation of these small population groups. This study reports factors that guided the cultural adaptation and administration of the National Cancer Institute's Health Information Trends National Survey (HINTS) for a United States-dwelling Pacific Islander population in Hawai'i. To adapt the survey, four focus groups were conducted with 32 purposively-selected Micronesian migrants. Themes on health, healthcare barriers, cancer and methods to implement the survey were extracted from the analyses of the focus group narratives. Key cultural factors were identified that impact health practices, including religious and cancer fatalism, racism, health locus of control and other barriers. Using information from the focus group participants, the HINTS questionnaire was modified and the survey was implemented. The survey data provided will inform the future delivery of health promotion strategies for this unique medically underserved population.

Keywords

Cancer epidemiology, health communication, health promotion, qualitative research, health equity, cultural appropriateness, Micronesian

Introduction

According to the 2010 Census, 1.2 million people in the United States (U.S.) identified themselves as Pacific Islanders, one of the fastest growing U.S. populations.¹ Pacific Islanders represent a broad category of ethnically and culturally diverse groups. Although Micronesians are the third largest ethnic group, comprising 15% of U.S. Pacific Islanders,¹⁻³ they continue to be "invisible" in the U.S. There are tremendous gaps in knowledge about factors that influence their health and quality of life.^{1,2}

The majority of Micronesians have come to the U.S. under a series of treaties known as the Compact of Free Association (COFA). COFA was negotiated in the 1980s with three Micronesian nations, the Federated States of Micronesia, the Republic of the Marshall Islands, and the Republic of Palau, giving the U.S. certain rights and responsibilities. Citizens from these nations have unlimited entry into the U.S. without visas or limits on length of stays.⁴ Inadequate economic opportunities combined with insufficient healthcare systems in COFA jurisdictions are driving the Micronesian exodus, specifically to Hawai'i and Guam.⁵ This migration is also fueled by complex historical and

political relationships, including substantial nuclear weapons testing conducted by the U.S. military in the Pacific region between 1946 and 1958.⁵

Limited data is available on the health status of Micronesians in Hawai'i, Guam and the continental U.S. because of their inadequate representation in U.S. healthcare assessments and surveys.³ In Hawai'i, the Centers for Disease Control and Prevention (CDC) Behavioral Risk Factor Surveillance System (BRFSS) captures limited data on Chamorro or indigenous Guamanians, but remains inadequate in reaching other groups of Micronesians.³ This underrepresentation is in part due to the survey's sampling strategies, including the use of only landline telephones, which unintentionally excludes many Micronesians.³ Therefore, more appropriate survey methods are needed to assess disease risk, health status, health information seeking and healthcare utilization among Micronesians in Hawai'i.

Despite this lack of population-based data, indications are that Micronesians living in the U.S. and their home nations represent a large medically underserved population.^{3,4} High rates of both infectious and chronic diseases experienced by Micronesians in their homelands contribute to overall low life expectancies, averaging 12 less years of life than U.S. residents.⁵ Micronesian migrants to the U.S. continue these high disease burdens with significant prevalence of tuberculosis, obesity, diabetes and cancer. Recent study data and anecdotal evidence from organizations that provide healthcare to Micronesians in the Pacific including Tripler Army Medical Center, and Hawai'i's community-based health centers reveal a high and unequal burden of both chronic and infectious diseases, including cancer, diabetes, and cardiovascular disease.³ Micronesian women experience some of the highest rates of cervical cancer in the world with an incidence rate of 18.3 /100,000 compared to the U.S. rate of 7.2/100,000, which illustrate lack of access to routine cancer screening and prevention. Additionally, the unique cancer risk behaviors of Micronesians including tobacco and betel nut use are correlated with the incidence and mortality rates for lung, nasopharyngeal and liver cancers in this ethnic group.⁶

Improved assessment of the healthcare needs of this growing U.S. population can support appropriate health promotion and the strategic allocation of resources to reduce health inequities. One possible tool to help reach this goal may be the use of the

Health Information National Trends Survey (HINTS).⁷ HINTS was created in 2003 by the National Cancer Institute in an effort to assess the access and utilization of health information technology to promote health behaviors. However, HINTS has limited sampling data on Micronesians.⁷ As Micronesian migrants may have different needs and protocols than the general population, focus groups with Micronesian community members were conducted to identify the appropriate adaptations needed to successfully administer HINTS to this group.^{8,9} Key factors to understanding the health behaviors and perceptions of Micronesians were identified. Findings from the preliminary qualitative research are reported here.

Methods

This study was approved by the University of Hawai‘i’s Office of Research Compliance. Focus groups (n=4) were conducted from 2012-2013. Thirty-two migrants from either Chuuk (a state within the Federated States of Micronesia) or the Republic of the Marshall Islands participated. These populations were chosen as they represent the largest Micronesian demographic groups in Hawai‘i.¹⁰

Participants were referred from the Hawai‘i Department of Health’s Bilingual Health Services’ Easy Access Program (DOH-EAP), which provides linguistically- and culturally-appropriate healthcare assistance to Hawai‘i’s immigrants.¹¹ People who had vocational or positional influence within Hawai‘i’s Chuukese or Marshallese communities were given priority for inclusion because of their capability to provide rich information about community members in their respective groups.^{9,12,13} Focus groups were stratified by ethnic group (separate sessions were held for Marshallese and Chuukese groups) and gender to accommodate language differences and gender norms that might otherwise deter free conversation in Pacific Island cultures.¹⁴⁻¹⁶ Trained moderators, recruited from the Hawai‘i DOH-EAP and matched by ethnicity and gender, led the groups and signed non-disclosure agreements. All participants provided written and oral consent to voluntarily participate.

Focus groups were held at a health center serving Honolulu’s Chuukese and Marshallese communities and were audiotaped. Interview questions were designed to obtain data about: the relevance of health and cancer including cultural factors related to health; how health information is disseminated; willingness to participate; and the culturally-appropriate methods for administering a health survey within the Marshallese or Chuukese community (Table 1).

Table 1. Questions Used for Discussion Group Interviews
Section 1 – General Health and Cancer:
1. What does health or being healthy mean to you?
2. What does cancer or a cancer diagnosis mean to you?
3. How does cancer impact your community?
Section 2 – Health and Culture
1. What are the customs in the Chuukese/Marshallese culture that would make you feel uncomfortable answering questions surrounding cancer and health?
2. What could be done to help make you feel more comfortable?
3. Do you or how do you share health/cancer information with the public in Chuuk/ the Marshall Islands?
4. How have you ever answered questions about health/cancer?
5. How could we best ask questions about health with Chuukese/Marshallese people
6. How could we get Chuukese/Marshallese people together to ask health questions?
7. What has been your experience in obtaining healthcare, have you experienced discrimination in this setting?
Section 3 – Survey Design and Administration
1. What customs in the Chuukese/Marshallese culture would support people answering a survey about health and cancer?
2. What do you think is the best way we can reach people from the Chuukese/Marshallese community to promote taking a survey?
3. What would make you and other Chuukese/Marshallese people more likely to agree to answer survey questions surrounding cancer?
4. How important would it be to administer the survey in the Chuukese or Marshallese language?
5. If a written survey is used, how much help would people need to complete a survey?
6. How important would it be to have someone who is Chuukese/Marshallese help administer the survey?
7. How much time would people be willing to give to complete a survey?

All dialogue of the four focus groups were translated into English by the bilingual moderators and subsequently transcribed by the study team. Analysis of the transcribed interviews was inductive.^{12,16} Members of the study team independently read the transcripts to identify potential themes and structures. Consensus was established among the study team for a structural framework that encompassed themes and underlying meanings and was then used to establish a coding structure for investigator co-coding.^{8,12} The study investigators then reread the transcripts, highlighting illustrative passages. There was high agreement among the investigators on themes and any disagreement was discussed until consensus was reached. The results of the investigators' analysis of the transcripts were reviewed by the focus group moderators and transcript translators who, as representatives of the Marshallese and Chuukese communities, supported this study's use of a member-checking procedure to ensure the accuracy of the findings, and to provide any additional insights concerning the data.^{12,13}

Results

A total of six Chuukese and six Marshallese women, and 10 Chuukese and 10 Marshallese men participated (Table 2). Five major themes were identified: (1) perceptions about health; (2) communications about health; (3) cultural factors influencing health; (4) perceived racism in healthcare; and (5) survey method considerations. Each is discussed in more detail below.

Perceptions About Health

Definitions of health were wide ranging. For instance, some saw the absence of medical care as a sign of health. A Marshallese man stated, "One is healthy if he is not being treated by the doctor or doesn't have to take medication." A Chuukese woman linked health to financial well-being and having a social support system, stating, "Knowing that I have a home, a job and family support is healthy to me."

Perceptions about cancer differed between the two groups. Marshallese discussions focused on the role of nuclear testing as a causal factor of cancer. A male Marshallese stated, "Our community suffers because of the nuclear bombs dropped on our homes." Another Marshallese man reiterated and expanded this concept:

We think cancer in the Marshalls is related to the bomb testing. I have seen many Marshallese coming to Hawai'i for cancer-related medical treatment; and some did not make it... Back home we have seen babies born without bones because of the fallout.

On the other hand, Chuukese participants saw cancer as a rare disease, possibly related to the limited access to treatment and the non-disclosure of patients' disease in their community. A Chuukese man stated emphatically for the group, "Cancer is rare for us, it is not common."

	n (%)
Chuukese	
Male	10 (31)
Female	6 (19)
Marshallese	
Male	10 (31)
Female	6 (19)
Total	32 (100)

Participants across all groups had remarkably fatalistic attitudes toward a cancer diagnosis: most associated cancer with impending death, and the few patients that survived were considered lucky. Early stage cancers were not associated with better survival rates or cures. One Marshallese man stated, "Getting diagnosed with cancer means that you are going to die soon; that you don't have much more time on Earth."

The financial costs of cancer care also seemed to frame participants' attitudes. A Marshallese man stated, "I think about the money and the debt; because if you have money, you have a big chance of surviving the cancer, but if you don't have money, I'm sorry, bye-bye."

Communicating About Health

Communication about health is often restricted among these populations. One Chuukese woman said, "Cancer is not talked about even among family members. Some have cancer but we don't know because we don't get treatment." Across all groups, participants emphasized that cancer and the notion of death from cancer are uncomfortable topics. However, younger generations could be more willing to talk about health and cancer. A Marshallese woman stated, "There are youth-to-youth programs that use skits and music to talk about health."

Similarly, all participants shared that certain topics are considered taboo in discussions, particularly in mixed gender groups in Micronesian culture. Participants stated that open discussions about breast, cervical, prostate and colorectal cancers as well as the associated screening tests are inappropriate in mixed gender groups. A male Marshallese emphasized, "You'd have to frame questions and information related to sexual organs in a certain way. In the older generation, [cancer] might be taboo to talk about; the younger ages are more willing." The norms supporting gender concordance extend to personal interactions with healthcare providers. Another Marshallese woman explained, "Females would prefer to see a female physician, especially when talking about reproductive parts. Otherwise it is very uncomfortable to talk about these things."

A wide range of communication channels was used to obtain and disseminate health information in both communities. Popular health communication channels included use of the Internet, radio, television, brochures, and posters. Among Marshallese participants, churches were described as a setting to discuss health information. One Marshallese man stated, "Churches might be a good place to share cancer information. The Marshall Islands government had a church-based program teaching people about cancer." By contrast, some Chuukese people felt uncomfortable sharing personal health information in church-based groups. One Chuukese man stated, "We don't like to share the secrecy of our own health in groups, churches may not work for that reason."

Cultural Factors Influencing Health

The discordance between Western and Micronesian perceptions of large body sizes was common across all discussions. A Chuukese female stated, "In Chuuk, the mentality of being healthy is being chubby. They tell you to feed your kids so that they look healthy, but we know that's not true." Another Chuukese woman stated, "In Chuuk if you are fat you are healthy, otherwise people will worry you are sick or your husband isn't treating you well. Skinny is not healthy."

There were also conflicting beliefs about Western and traditional medicine. One Chuukese male shared that he put his faith in Chuukese traditional medicine, "I don't go to church or to the doctor, I go to the person...[who] knows how to make medicine. . . I believe in the ingredients in the plants to heal."

Perceptions of Racism in Healthcare

Perceived racism emerged as an important factor which not only influenced health care decision making but dominated other aspects of migrants' daily lives in Hawai'i. A Marshallese woman raised her concerns of racism in the healthcare system by stating, "There is like a stigma with the government, the healthcare system in Hawai'i... When we get sick and we need services, but we are not eligible. We have an agreement with the U.S. to be here and to work here. Yet we are still treated like you know [inferior]."

A Chuukese woman said, "We breathe racism, we experience it every day of our lives here. Just wearing our dress is a big turn-off for people, but some of us make a point to wear it so you cannot forget us." Male respondents had similar views of racism in health care settings. One Chuukese man explained that he felt like his doctor ignored his concerns, "...so my concern is he didn't listen to me and check me for my prostate when I say this has been my problem. So I was thinking, I am not like him." This view is shared by the Marshallese men. One Marshallese man said, "They talk to us like we are stupid and we don't understand anything."

Survey Methods Considerations

Participants emphasized that surveys should be brief and easy to use. A Marshallese man indicated that it was essential to deliver the survey face-to-face, translate it into their language, have community leaders administer them and provide refreshments and transportation. The location for the administration of the survey and transportation to the site were of utmost importance to all participants. One Chuukese man stated, "Trying to find a central place is hard because the Chuukese community is spread out across the island. The only reason I'm here is because...I live close to here."

All participants emphasized that the research be conducted in an open fashion using groups and that investigators should take time to become acquainted with participants during the survey administration sessions. As a Marshallese man noted:

It is hard to get people to come out for focus groups and surveys because many people want to do research on us. It is important for us know how it will benefit our community. If people know it will help them get better cancer services they will be more willing to answer questions.

Finally, participants suggested gift cards from a local supermarket were appropriate incentives. According to a Marshallese woman, "If you are going to give gift cards, then people will be more willing to answer a three- or four-page survey. We would stay for two hours but with incentive. More than an hour with no incentive [is not good]."

Discussion

The present study illustrates attitudes among Marshallese and Chuukese people residing in Hawai'i about health, cancer, racial discrimination and participation in health-related surveys. Previous studies have identified the role of socioeconomic and political factors contributing to the health disparities found in Micronesians, including the legacy of U.S. nuclear testing contaminating subsistence resources and leading to dietary risks for disease as well as the resulting cancers caused by fallout. Within the jurisdictions, inadequate employment, educational opportunities and healthcare systems remain, despite the requirements of the COFA to provide these services in remuneration for the U.S. military presence. These factors contribute to poor health outcomes and drive the current migration of Micronesians. Once in Hawai'i, Micronesians experience discrimination in the society at large and in the health care system.¹⁸ In the past, the state of Hawai'i has discriminated against Micronesians by unconstitutionally attempting to dis-enroll them from Medicaid.¹⁸ Our study sought to identify these additional social determinants of health unique to Micronesians in Hawai'i to include in the survey design to provide a more robust assessment of health. Results from the group discussions were instrumental in guiding the modification and implementation of HINTS to

fit Micronesian migrants living in Hawai'i. Items added to the original HINTS instrument included measures of cancer fatalism, health locus of control, religiosity, perceptions of racism, and acculturation. Appropriate instruments to assess these factors were selected through a review of published scales.

In many ethnic minority populations, fatalism towards cancer or the belief that death is inevitable when cancer is present is thought to influence cancer screening practices and treatment adherence.²⁰ The analyses found that this attitude was prevalent for the study participants. Therefore, items derived from Powe Fatalism Inventory were included for this audience.²¹ Related to the findings from the focus groups, distinct health locus of control (HLC) perspectives may be a major factor in Micronesian populations. Participants expressed differences in their attribution of cancer causes; some participants focused on external causes (nuclear testing) while downplaying internal factors (tobacco and betel nut use). For this reason, an HLC instrument was included to assess these differences across Marshallese and Chuukese groups.

Religious practices and spiritual life are considered important aspects of health in many Pacific Islander communities and may affect health seeking behaviors.^{15,16} According to the World Fact Book,¹⁷ 94% of Micronesians identify themselves as Christian (Catholic or Protestant).¹⁹ Those beliefs exert a positive influence in coping with illnesses by providing mechanisms for social support. In the focus groups, spiritual health was commonly mentioned as an important feature of overall health. Given this finding, items for positive and negative religious coping as measured by the Religious Coping Activity Scale (RCOPE)²² were added to the modified HINTS instrument.

During the four focus group discussion sessions, most participants said they had experienced some form of racial discrimination. This finding supports a need to quantify experiences of racial prejudice in this group, as racism may affect their healthcare seeking behaviors and overall health.²³ Items from a scale developed by Carty, et al, (2011) were added to explore how perceived racism potentially affects health outcomes in this group.²⁴ Additionally, because many Micronesian people said they experienced racism due to their immigration status, items from an acculturation scale for Pacific Islanders were added.²⁵ It was anticipated that the use of these scales might help characterize the effects of racism and acculturation on the health and health seeking behaviors of Micronesians in Hawai'i.

Findings regarding the survey administration procedures suggested that the survey should present questions in a bilingual format, displaying content in both English and the appropriate Micronesian language, side by side. Participants suggested administering surveys to a group, allowing the study team to explain the purpose of the survey and to build trust with participants. To adhere to these recommendations, collaboration was

extended to the DOH-EAP, asking for help to create bilingual versions of the modified HINTS survey, provide guidance on potential venues to administer the survey and serve as facilitators during the planned group administrations of the survey.

There were several limitations in this research. First, there was a lack of cultural concordance between the research team (none of the research team members identified as Pacific Islander) and the community of interest. A second limitation was that participants were recruited through one government program. This method may have introduced response bias, as recruited participants may have had an affinity towards the research topic or commonalities on factors related to the inquiry. Also, despite efforts to segregate focus group members by age and gender, some interviewees may have deferred their comments to accommodate members of higher status in the community.

However, the rich detailed data provided by the interviewees in this study met the exploratory purpose of this research.²⁶ The use of an inductive approach to the data analysis was intended to address any limitations relative to sampling by allowing the findings to emerge from the data rather than adhering to a prescribed framework.

Conclusions

Participants highlighted several factors including religiosity, fatalism, and racism that may potentially contribute to Micronesians' knowledge and use of health information and services. These factors informed the modification of the HINTS instrument. Information shared during the focus groups led to the delivery of the survey in group settings and in nontraditional administration venues including public parks, which were more in line with cultural protocols. These findings are especially consequential for those conducting national surveys in that to reach elusive or underrepresented populations, such as Micronesians, it is important to include them in the research planning process.

Conflict of Interest

None of the authors identify a conflict of interest.

Disclosure Statement

This work was supported by a grant (NCI-U54 1U54CA143727) from the National Cancer Institute.

Authors' Affiliations:

- University of Hawai'i Cancer Center, Honolulu, HI (KC, MKIH)
- University of Hawai'i at Mānoa, Honolulu, HI (HL)
- College of Liberal Arts & Social Sciences, University of Guam, Mangilao, Guam (LPS)
- College of Natural & Applied Sciences, University of Guam, Mangilao, Guam (GB)

Correspondence to:

Kevin Cassel DrPH; University of Hawai'i Cancer Center, 701 Ilalo St., Honolulu, HI 96813; Email: kevin@cc.hawaii.edu

References

1. Hixon L, Hepler BB, Kim MO. The Native Hawaiian and Other Pacific Islander Population: 2010 Census Briefs: U.S. Department of Commerce. Available from: <http://www.census.gov/prod/cen2010/briefs/c2010br-12.pdf>.
2. Ohtsuka R, Ulijaszek S. *Health Change in the Asia Pacific Region: Biocultural and Epidemiological Approaches*. New York: Cambridge University Press, 2007.
3. Pobutsky A, Krupitsky D, Yamada S. Micronesian Migrant Health Issues in Hawai'i. *California Journal of Health Promotion*. 2009;7(2):32-35.
4. Palafox NA, Hixon AL. Health consequences of disparity: the US Affiliated Pacific Islands. *Australasian psychiatry: bulletin of Royal Australian and New Zealand College of Psychiatrists*. Jul 2011;19 Suppl 1:S84-89.
5. Riklon S, Alik W, Hixon A, Palafox NA. The "compact impact" in Hawaii: focus on health care. *Hawaii Med J*. 2010;69(6 Suppl 3):7-12.
6. Hernandez BY, Bordallo RA, Green MD, Haddock RL. Cancer in Guam and Hawaii: A comparison of two U.S. Island Populations. *Cancer Epidemiol*. 2017;50(Pt B):199-206.
7. Rizzo L, Moser RP, Waldron W, Wang Z, Davis W. *Analytic Methods To Examine Changes Across Years Using Hints 2003 & 2005 Data*. Bethesda, MD: National Cancer Institute; June 2008.
8. Krueger R, Casey MA. *Focus Groups, A Practical Guide for Applied Research*. Third ed. Thousand Oaks, CA: Sage Publications, Inc.; 2000.
9. Maxwell J. *Qualitative Research Design, an Interactive Approach*. Vol 42. London: Sage Publications; 2005.
10. Department of Business Economic Development and Tourism. *The State of Hawai'i Data Book 2013*. Honolulu: State of Hawai'i; 2013. Available at <http://files.hawaii.gov/dbedt/economic/databook/2013-individual/01/013713.pdf>.
11. Hawai'i Department of Health. 2014. Available at: <http://health.hawaii.gov/bilingual-services/>.
12. Charmaz K. *Constructing Grounded Theory*. Los Angeles: Sage Publication; 2006.
13. Patton MQ. *Qualitative research and evaluation methods*. 3 ed. London, UK: Sage Publications; 2002.
14. Aitaoto N, Braun K, Estrella J, Epeluk A, Tsark J. Design and Results of a Culturally Tailored Cancer Outreach Project by and for Micronesian Women. *Preventing Chronic Disease*. 2012;9:100262. DOI: <http://dx.doi.org/10.5888/pcd9.100262>.
15. Aitaoto N, Braun KL, Dang KL, So'a T. Cultural considerations in developing church-based programs to reduce cancer health disparities among Samoans. *Ethnicity & Health*. Sep 2007;12(4):381-400.
16. Hubbell FA, Luce PH, Afeaki WP, et al. Legacy of the Pacific Islander cancer control network. *Cancer*. 2006;107(S8):2091-2098.
17. U.S. Central Intelligence Agency. Micronesia, Federated States of 2014. Available at <https://www.cia.gov/library/publications/the-world-factbook/geos/fm.html>.
18. Shek D, Yamada S. Health care for Micronesians and constitutional rights. *Hawaii Med J*. 2011;70(11 Suppl 2):4-8.
19. Hezel F. Christianity in Micronesia Micronesian Seminar 2010. Available at <http://micsem.org/pubs/articles/religion/frames/christmicrofr.htm>.
20. Powe BD, Hamilton J, Brooks P. Perceptions of cancer fatalism and cancer knowledge: a comparison of older and younger African American women. *Journal of Psychosocial Oncology*. 2006;24(4):1-13.
21. Powe BD. Perceptions of cancer fatalism among African Americans: the influence of education, income, and cancer knowledge. *Journal of National Black Nurses' Association*. Fall-Winter 1994;7(2):41-48.
22. Pargament KI, Koenig HG, Perez LM. The many methods of religious coping: development and initial validation of the RCOPE. *Journal of Clinical Psychology*. Apr 2000;56(4):519-543.
23. Ahmed AT, Mohammed SA, Williams DR. Racial discrimination & health: Pathways & evidence. *The Indian Journal of Medical Research*. Oct 2007;126(4):318-327.
24. Carty DC, Kruger DJ, Turner TM, Campbell B, DeLoney EH, Lewis EY. Racism, health status, and birth outcomes: Results of a participatory community-based intervention and health survey. *Journal of Urban Health*. Feb 2011;88(1):84-97.
25. Novotny R, Williams AE, Vinoya AC, Oshiro CE, Vogt TM. US acculturation, food intake, and obesity among Asian-Pacific hotel workers. *Journal of the American Dietetic Association*. Oct 2009;109(10):1712-1718.
26. Clarke A. *Situational Analysis, Grounded Theory After the Postmodern Turn*. London: Sage Publications; 2005.