

Cancer Assessment Methodology in a Native Hawaiian Community

Andrea Siu, BA, and Donna-Marie Palakiko, RN, MS

Ke Ola Mamo, Native Hawaiian Health Care System, O'ahu

WHAT IS THE PURPOSE OF THIS STUDY?

- To present the experiences of a research team that modified standard community-based participatory research (CBPR) methods to bring them in line with traditional Native Hawaiian culture. The team modified widely used protocols for data collection and standard survey practices in its conduct of a door-to-door health survey among residents of a Native Hawaiian community. The team, for instance, did not directly approach a home and knock on its door. Instead, researchers called out to residents from the edges of the property before approaching the home. The survey concerned the residents' experiences with cancer.

WHAT ARE THE PROBLEMS?

- In comparison with other ethnic groups in Hawai'i, Native Hawaiians have both higher incidences of late-stage cancer diagnoses and higher mortality rates from cancer.
- Limited data exist regarding the impact of cancer on Native Hawaiian communities.
- Needs assessment surveys must be done to prepare researchers to develop appropriate interventions and programs.

WHAT ARE THE FINDINGS?

- When researchers plan to assess minority communities, especially about sensitive subjects such as cancer, they must use methods that are grounded in an understanding of that group's cultural sensitivities; they must also involve members of the minority group.
- Research protocols based on both traditional Native Hawaiian approaches to gathering information and standard randomization schemes seemed to strike residents surveyed in this study as being exclusive, rather than inclusive. This perceived exclusivity often deterred the residents from participating in the study.
- By using door-to-door assessments (as opposed to surveys done by telephone or mail), the researchers increased the visibility of the organizations involved in the study. These face-to-face encounters also created opportunities for members of the research team to offer on-the-spot assistance.
- Even greater levels of involvement on the part of community members as researchers in CBPR projects are needed to increase the willingness of other members of a given community to participate in health research surveys.

WHO SHOULD CARE THE MOST?

- Organizations that want to assess health issues affecting a given community to develop appropriate interventions and programs that address health disparities.
- Organizations interested in assessing the health status of people within Native Hawaiian communities.
- Organizations and researchers interested in improving the health of Native Hawaiians.
- Organizations interested in forming CBPR partnerships.

RECOMMENDATIONS FOR ACTION

- Increase the role of community members in research. Do this especially through the CBPR process.
- Adapt a sampling procedure that strikes survey participants as inclusive, rather than exclusive.
- Build strong partnerships to share the burden of carrying out face-to-face health surveys.