Using a Community-Based Participatory Approach to Create a Resource Center for Native Hawaiian Elders

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Published: 19 December 2008

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Education for Health, Volume 20, issue 3, 2008

Available from: http://www.educationforhealth.net/

A B S T R A C T

Context: Historically, Native Hawaiian elders have been recognized as the major sources of wisdom and transmitters of knowledge and training to younger generations. Yet, concerns exist today for these elders who experience shorter life expectancies, poorer health and greater disability than elders in other ethnic groups in Hawai`i.

Objective: We describe Hā Kūpuna: National Resource Center for Native Hawaiian Elders, established at the University of Hawai`i to address disparate health and improve the access and delivery of services to these elders.

Method: Hā Kūpuna is described in accordance with the principles of community-based participatory (CBP) research with its unique emphasis on culturally competent practice.

Results: Application of the CBP approach is illustrated in the following steps: community engagement; development of an infrastructure; implementation and dissemination of research and technical assistance projects; and evaluation.

Discussion: The CBP approach is highly relevant for Native Hawaiians because of its alignment with cultural values, the mobilization of the community and the emphasis on reducing health inequities through social change. In adhering to a CBP approach to improve the health of elders, Hā Kūpuna seeks to perpetuate the culture through the transmission of hā (breath) from older to younger generations.

Keywords: Native Hawaiian elders, community-based participatory research, culturally-competent practice, long-term care, caregivers
Context

Elders in Native Hawaiian culture historically have been recognized as the major sources of wisdom and the transmitters of knowledge and training to younger generations. In ancient times (wa kahiko), before contact with other civilizations in 1778, the spoken word and the memories of elders were the texts of learning (Pukui et al., 1979). In a symbolic ceremony called hā (breath), specialized knowledge and training were transmitted by an elder breathing into the mouth or fontanel of another person.

After 1778, contact with western and eastern civilizations increased the diversity of Hawai’i’s population. Today, Native Hawaiians comprise 20% of the approximately 1.2 million residents of Hawaii; other major ethnic groups include Whites (about 25%), Japanese (about 23%), Filipinos (about 17%) and Chinese (about 5%) (U.S. Census Bureau, 2001). The role of Native Hawaiian elders, or kūpuna, today may not be the same as that of wa kahiko, but there is still great importance in the transmission of values, knowledge and skills to younger generations.

Concerns, however, exist for the approximately 41,000 Native Hawaiian kūpuna residing in Hawaii, and the 23,000 living outside of Hawaii (U.S. Census Bureau, 2000). These concerns are most clearly documented for those in Hawaii, with a scarcity of information for kūpuna residing outside of Hawaii. In general, kūpuna in Hawai‘i have shorter life expectancies, poorer health and greater disability than elders in other ethnic groups in the state (Braun et al., 1996; Kana‘iaupuni et al., 2005). They are also more likely to have poor socioeconomic status and underutilize some services compared to their non-native elder counterparts in Hawai‘i (Mokuau et al., 1998). The low utilization of services may be due to universal barriers for older Americans, such as the fragmentation of health care services and rising costs, but may also be influenced by factors specific to Native Hawaiian elders, such as living in a multiple-island community in which there is limited availability and accessibility to services for rural residents.

The high social and health risk profile of Native Hawaiian elders predisposes their susceptibility to needing long-term care. In one of the few surveys conducted with kūpuna, they identified their children and spouses as their primary supports in the home, with limited utilization of paid, or formal, caregivers (Alu Like, 2005). They further indicated that financial concerns restrict their quality of life, and that community services providing “free or reduced-priced meals” and transportation were important complements to home care. Such preliminary information is suggestive of more complex problems and underlines the need for more research. This need for research is amplified when viewed in the context of the dramatic increases in the aging population in Hawaii from 12 percent in 1980 to a projected 25 percent in 2020 (State of Hawai‘i, Department of Health, Executive Office on Aging, 2006). Research which seeks to understand the challenges of kūpuna and to identify solutions to resolve their disparate health can be optimized when the university and community are partners.

The purpose of this article is to describe Hā Kūpuna: National Resource Center for Native Hawaiian Elders and its efforts to improve long-term care for kūpuna. Information on establishing Hā Kūpuna in accordance with the principles and practices of community-based participatory (CBP) research is provided. The discussion highlights the advantages in mobilizing CBP partnerships for a native population.

Method – Establishing a Resource Center

Hā Kūpuna was established at the University of Hawai‘i School of Social Work in September 2006 with funding from the U.S. Administration on Aging, Department of Health and Human Services (AoA). The AoA provides national leadership in the
development and funding of a comprehensive system of home and community-based services for older people and their family caregivers, and is charged with supporting Resource Centers that specifically target native populations including older Indians, Alaska Natives and Native Hawaiians (U.S. AoA, 2006).

Hā Kūpuna is a university-community partnership grounded in a CBP approach to health research. The W.K. Kellogg Foundation Community Health Scholars Program defines CBP research as the:

"collaborative approach to research that equitably involves all partners in the research. [It] begins with a topic of importance to the community, [and] has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities." (Community-Campus Partnerships for Health, n.d.).

Community participatory partnerships emphasize the role of values as well as dialogic methodologies in mediating research (Guba, 1990). For example, the values and priorities of participants will determine the direction of research, and their interactive dialogue will influence the results and outcomes. CBP research strongly contrasts with more conventional research which is based on natural laws, objectivity and the use of experimental methodologies.

The principles of CBP research emphasize building upon the local knowledge of the community, relying on and strengthening community resources and improving community health (Fong et al., 2003; Israel et al., 2001). Within this context, specific principles which guide Hā Kūpuna include: (a) striving to reduce health inequities for Native Hawaiian elders; (b) building on the strengths and resources of the community; (c) including community participants in major phases of the research process; (d) promoting the capacity and collaborative networking of participants; (e) disseminating information to the community; and (f) adhering to ethical guidelines in conducting research.

Within the purview of CBP principles is the assumption of cultural competence (Association of Asian Pacific Community Health Organizations, 2002). Cultural competence refers to the capacity of an individual or organization to effectively respond to the needs of diverse cultural groups and can be viewed as a potential strategy to decrease health disparities in ethnic minority communities (Brach & Fraser, 2000). The strategy involves Native Hawaiians at every level of research and employs an understanding and application of the history, values and behaviors of the population in the formation of issues and solutions.

In line with CBP research principles, and with specific attention to cultural competence, Hā Kūpuna seeks to assure the transmission of hā from older to younger generations. Its goal is to improve access and delivery of services to Native Hawaiian elders and their family caregivers through research on health and long-term care needs. In accordance with a CBP approach, Hā Kūpuna was established through the following steps: engagement with the community; development of an infrastructure; implementation and dissemination of research and technical assistance projects; and evaluation.

Results - Application of a CBP Approach

Engagement

Engagement is the first step in the development of successful partnerships and is characterized as contact with a clear purpose, open communication and a commitment to mutual goals and directions (Kirst-Ashman & Hull, 2006). Prior to applying for the
grant to the AoA, the principal and co-investigators of Hā Kūpuna engaged a diverse array of leaders and stakeholders who could potentially be impacted by its establishment. These people included congressional leaders, national leaders in native elder health, leaders at the University of Hawai‘i, gerontologists, Native Hawaiian leaders in the community, and Native Hawaiian elders. A series of meetings fostered open discussion about the priorities and activities that the community leaders felt were important. Given the paucity of information on Native Hawaiian elders, stakeholders easily concurred on the priorities related to the need to provide technical assistance and conduct research that would generate information on this population. As a result of the meetings, it was determined that Hā Kūpuna should focus on health and long-term care to kūpuna and their families through the development and dissemination of knowledge. Once the project was funded by the AoA, engagement continued to be interwoven into every aspect of Hā Kūpuna operations.

**Developing the Infrastructure**

The organizational infrastructure should clarify roles and responsibilities for partnerships and build opportunities for sustainability (Israel et al., 2001). In its first year of operation, Hā Kūpuna worked to build a sustainable organizational infrastructure by securing financial support for core staff from university administration, carefully considering the roles and activities that would enhance continued funding from the AoA and applying to other venues for additional resources. For example, efforts were undertaken to apply for additional grant support from two Hawai‘i organizations whose interests intersect with Hā Kūpuna in research on kūpuna and family caregivers. Academic institutions are in a good position to seek such funds, and in doing so they increase their credibility within the community, and enhance the potential that other funds can be successfully sought (Israel et al., 2001).

The responsibilities for the design and delivery of Hā Kūpuna are shared by several people, including the co-investigators and a coordinator who oversees operations. Hā Kūpuna staff sought to strengthen community relationships with more clearly designated collaborative roles for community partners. For example, Hā Kūpuna has formalized its partnerships with key leaders in Native Hawaiian and gerontology networks through the creation of two advisory councils—a 5-member Native Advisory Council (NAC) and a 10-member Partner Organizations Advisory Council (POAC). Both advisory councils have a commitment to reducing health inequities for kūpuna and have the far-reaching capacity to solicit and disseminate information to diverse groups of people. The NAC is comprised of renowned Native Hawaiian leaders, three of whom are elders, who assure that the direction and activities of Hā Kūpuna are culturally-competent, and the POAC is comprised of service providers in the aging network who provide guidance in community-driven gerontology priorities. In addition to separate council meetings, there are also joint meetings that foster collaboration and capacity-building among these two groups. There is generally consensus on work; however, if there is any disagreement, the opinions of those advisors who are Native Hawaiian elders typically take precedence.

**Implementing and Disseminating Research and Technical Assistance Projects**

The substantive work of Hā Kūpuna is in two fundamental areas: research and technical assistance. Priorities and plans for both areas were developed with input from the NAC and POAC, with feedback from other key leaders in the broader community, and with information from the general literature. Technical assistance projects are intended to improve the capability of community organizations to deliver a range of services. For example, Hā Kūpuna, in support of research engineered by the National Resource Center on Native American Aging (NRCNAA) (National Resource Center on Native American Aging, 2006), provided technical assistance to two Hawai‘i organizations utilizing an NRCNAA survey of elder needs. Hā Kūpuna had a role in tailoring the research protocols for each organization and training the interviewers to administer the survey in Native Hawaiian communities. Since the technical assistance projects involved research, support with the application to the Institutional Review Board to assure
the rights and welfare of human participants was also rendered. Training community participants on the standards and rigor needed to assure ethical conduct is fundamental to community-based research (Tse & Palakiko, 2006). Beyond Institutional Review Board requirements, Hā Kūpuna upholds general principles of ethical conduct, including respect for human dignity, right to confidentiality and belief in community ownership of data. For example, we respect the right of Native Hawaiian communities to “own” their own research data, and after assisting them with research design, data collection and analysis, we will turn over all data to them for their use. Community partners have gone on to use the data in community publications and grant proposals. One partner asked Hā Kūpuna for help with grant proposals, and has since secured funds to offer chronic disease self-management programs to kūpuna on five islands.

With regard to a research agenda, Hā Kūpuna developed a two-pronged focus: (a) an examination of historical influences on the resiliency and well-being of kūpuna, and (b) an assessment of contemporary health and long-term care needs, patterns and preferences of Native Hawaiian elders and their family caregivers. Research in the first area provides a conceptual framework and suggests that aging is influenced both by historical events and resiliency factors (e.g. cultural values and traditions) that ultimately shape Native Hawaiian life trajectories. Thus, research examining kūpuna well-being must acknowledge that health is the product of cumulative risk and protective factors that are best understood from a life course perspective (Elder, 1994).

Research assessing contemporary health status and long-term care for kūpuna is strongly warranted due to the paucity of information. Qualitative methods, such as key informant interviews and focus groups, are appropriate for this type of formative research which seeks to define the target population, identify relevant issues and develop interventions (Morgan, 1993). These methods have unique cultural applicability because of Native Hawaiians’ oral-aural tradition, preference for collective learning and emphasis on face-to-face meetings that allow people to gauge trustworthiness (Braun et al., 2002). The use of qualitative methodology was strongly supported by Native Hawaiian elders on the NAC, and Hā Kūpuna staff have been supported by advisors to conduct key informant interviews and focus groups with leaders in the gerontology and Native Hawaiian health fields, kūpuna and family caregivers.

The involvement of Native Hawaiians in research occurred at multiple levels. Examples include involvement as research advisors when protocols are designed and proposals written, as data collectors and interpreters, and as respondents in key informant interviews and focus groups. Preliminary data from data-gathering efforts suggest that Native Hawaiian elders want to remain in their homes as they age; recognize the lack of community resources to support their family caregivers; are concerned about the lack of public transportation; and are troubled by the lack of caregivers and long-term care facilities. Data from these qualitative studies inform future studies which will incorporate both qualitative and quantitative methods.

The dissemination of information generated from research is an integral part of a CBP approach in which there is a collaborative sharing of results. Information on Hā Kūpuna’s research and technical assistance projects is disseminated through multiple venues, including a website (http://manoa.hawaii.edu/hakupuna), community presentations, academic conferences and publications. All of Hā Kūpuna’s dissemination efforts target key constituents, including: (1) Advisory Council members; (2) Native Hawaiian and gerontology organizations; (3) Native Hawaiian elders and their families; and (4) research, policy and practice communities interested in services for native elders. The penetration into the Native Hawaiian community via our key constituents is deep and reaches the five largest islands in the state of Hawai‘i, Hawaiian homestead communities where residents have at least 50 percent Hawaiian blood (State of Hawaii, Department of Hawaiian Home Lands, 2008) and other rural neighborhoods where kūpuna reside.
Conducting Evaluation

In addition to counting the number of new projects and publications, evaluation indicators for Hā Kūpuna track the development of a model infrastructure for university-community partnership, increased collaboration among elder service providers and Native Hawaiian leaders and increased knowledge about Native Hawaiian elders and long-term care. At the end of its first year, Hā Kūpuna evaluated its work by surveying advisory council members using a questionnaire modified from the Detroit Community-Academic Urban Research Center (Lanz et al., 2001). The questionnaire consisted of 17 items rated on a 5-point Likert scale assessing perceptions of general satisfaction, organization and structure of meetings, community-based research and impact. In addition, the questionnaire included two open-ended questions on the “good things” that happened as a result of Hā Kūpuna and “other things” Hā Kūpuna can do, and some demographic information on advisors (e.g. years working in gerontology or Native Hawaiian health). Members of both the NAC and the POAC who attended the last meeting of the year (n=11) completed the questionnaire. Overall, advisory members were satisfied with Hā Kūpuna’s activities and progress and found its work to be relevant to the greater community (Table 1). For example, ten (91%) advisory members agreed or strongly agreed that Hā Kūpuna stimulates collaboration by bringing together participants from the community and academia.

Table 1. Evaluation: Number (%) of Advisory Council Members that Strongly Agreed or Agreed with Each Item (N=11)

<table>
<thead>
<tr>
<th>Domain and Item</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Satisfaction</td>
<td></td>
</tr>
<tr>
<td>I am generally satisfied with the activities and progress of Hā Kūpuna during the past year.</td>
<td>11 (100)</td>
</tr>
<tr>
<td>I feel that the work undertaken by Hā Kūpuna is of high quality.</td>
<td>10 (91)</td>
</tr>
<tr>
<td>Organization and Structure of Meetings</td>
<td></td>
</tr>
<tr>
<td>Hā Kūpuna meetings are well-organized and conducted.</td>
<td>11 (100)</td>
</tr>
<tr>
<td>I find Hā Kūpuna meetings useful.</td>
<td>11 (100)</td>
</tr>
<tr>
<td>When our group makes decisions, appropriate follow-up action is taken by staff.</td>
<td>7 (64)</td>
</tr>
<tr>
<td>Community-Based Research</td>
<td></td>
</tr>
<tr>
<td>I feel that diverse opinions are allowed and respected at Hā Kūpuna meetings.</td>
<td>9 (82)</td>
</tr>
<tr>
<td>The work of Hā Kūpuna is relevant to the greater community.</td>
<td>11 (100)</td>
</tr>
<tr>
<td>Resources and strengths of the Aging Network, Hawaiian community, and academia have been brought together as a result of Hā Kūpuna.</td>
<td>10 (91)</td>
</tr>
<tr>
<td>Impact</td>
<td></td>
</tr>
<tr>
<td>I have increased my knowledge about aging processes during the past year.</td>
<td>9 (82)</td>
</tr>
<tr>
<td>I have increased my knowledge about special issues facing Native Hawaiian elders during the past year.</td>
<td>10 (91)</td>
</tr>
<tr>
<td>I have increased knowledge about health and long-term care resources for older adults during the past year.</td>
<td>7 (64)</td>
</tr>
<tr>
<td>I have increased my knowledge about other organizations concerned about Native Hawaiians and/or aging.</td>
<td>11 (100)</td>
</tr>
<tr>
<td>Hā Kūpuna successfully increases awareness of Native Hawaiian elders.</td>
<td>9 (82)</td>
</tr>
<tr>
<td>Hā Kūpuna creates new knowledge about Native Hawaiian elders.</td>
<td>9 (82)</td>
</tr>
<tr>
<td>Hā Kūpuna successfully disseminates new knowledge about Native Hawaiian elders.</td>
<td>6 (54)</td>
</tr>
<tr>
<td>Hā Kūpuna has increased our capacity to work together on issues affecting Native Hawaiian elders.</td>
<td>11 (100)</td>
</tr>
</tbody>
</table>

Discussion

Grounded in CBP principles, Hā Kūpuna is committed to research that informs social change which eliminates health disparities among Native Hawaiian elders. In its second year of operation, the work of Hā Kūpuna is still embryonic in nature, but it is anticipated that technical assistance which builds the capacity of organizations serving kūpuna, and research that elucidates the reasons and resolutions for health disparities can potentially influence social change. For example, social advocacy for alternative transportation can result from the understanding that the lack of public transportation places kūpuna at risk for obtaining needed
services, such as medical care. The availability of transportation in a multiple island community can improve service utilization, and potentially reduce health disparities. We are hopeful that in the future, recommendations generated from research will compel policy and services changes that will reduce inequities for kūpuna.

CBP principles focus on the collaborative networking of university-community partners to conduct research that builds upon the strengths of and benefits the community. These strengths are inherent in the perspective of cultural competence which prescribes an understanding of the history, values and behaviors of culturally diverse groups such as Native Hawaiians. There is clear alignment of CBP principles with Native Hawaiian history and worldview which emphasizes holism and interconnectedness as the basis for general well-being (Mokuau, 1996). Life in wa kahiko (ancient times) was guided by values that emphasized the collective rather than the individual, and clearly specified roles and behaviors for people in the community (Kamakau, 1964). Core Hawaiian values and behaviors reflecting the collective includes lokahi (unity and harmony), kuleana (responsibility, right) and kokua (helpfulness, cooperation). Native Hawaiian kūpuna in the community and on the advisory council prioritize these values in establishing Hā Kūpuna. For example, advisory council members affirmed the kuleana of Hā Kūpuna to educate the broader community on the needs of Native Hawaiian elders through the dissemination of information.

CBP research, which is dialogic and interactive, varies from conventional research and is highly appropriate for Native Hawaiians. Historically, conventional researchers have difficulty in thinking that a community, without any background in research, can significantly contribute to the research process (Ahmed et al., 2004). This mindset separates the university from the community, and creates a lack of respect for community knowledge. The consequence is that communities grow alienated and distrustful of university research. With conventional research, Native Hawaiians have typically been targeted as “research subjects,” but excluded as equal participants in the research endeavor. It has been reported that some Native Hawaiians have felt exploited by university research, believe such research to have limited benefit to the community and are thereby increasingly reluctant to participate in studies (Matsunaga et al., 1996). In contrast to conventional research, CBP research recognizes community knowledge and promotes reciprocal learning between the university and community. The Native Hawaiian community has already begun to acknowledge the compatibility of CBP approaches with Native Hawaiian culture (Banner et al., 1995; Braun et al., 2006; Matsunaga et al., 1996; Tse & Palakiko, 2006). Matsunaga et al. (1996) argue that participatory approaches ensure cultural competence because every stage of research promotes community knowledge. In the case of Hā Kūpuna, interactive dialogue between participants and staff influence the direction and scope of work. For example, Native Hawaiian service providers working with kūpuna want technical assistance in research, and Hā Kūpuna staff has developed research protocol designed to empower communities to conduct their own research.

CBP models offer evidence that the involvement of community members in research is more likely to produce meaningful change in a community (Ahmed et al., 2004). In this regard, research results can be utilized for action for social change, and for reducing inequities in communities. One example of a highly successful CBP model for Native Hawaiians is `Imi Hale – the Native Hawaiian Cancer Awareness, Research and Training Network (Braun et al., 2006). Funded by the National Cancer Institute, `Imi Hale demonstrates tangible results that focus on reducing the burden of cancer among Native Hawaiians through: (a) leadership by Native Hawaiians in the community; (b) national and regional funding of more than 30 research projects; (c) partnerships with more than 40 community organizations; and (d) more than 70 publications in referred journals. Already `Imi Hale has brought about social change by transforming the way cancer is viewed in the Native Hawaiian community, and it is anticipated that their work will have an impact on reducing inequities in cancer in future years.
In conclusion, the CBP alignment with cultural worldview and values, the promotion of community involvement and knowledge, and the emphasis on social change to reduce health inequities, makes the CBP approach highly relevant for Native Hawaiians. Several lessons emerge to guide Hā Kūpuna in the future:

- maintain the CBP approach for Native Hawaiian elderly,
- expand technical assistance and research capabilities to organizations in high density Native Hawaiian communities outside of Hawai`i where it is estimated that 23,000 elderly reside, and
- strengthen relationships with congressional leaders who can support legislation for Native Hawaiian elderly.

Now in its second year of operation, Hā Kūpuna adheres to a CBP approach, and seeks to generate credible and useful research to benefit Native Hawaiian elders. We believe this research which represents the voices of kūpuna, their caretakers and service providers, when disseminated, will help to transmit knowledge on this generation to younger generations. By emphasizing the health of elders who are the keepers of cultural knowledge and wisdom, Hā Kūpuna seeks to perpetuate the culture through the transmission of hā (breath).

References


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