



Published in final edited form as:

*Prog Community Health Partnersh.* 2008 ; 2(4): 329–340. doi:10.1353/cpr.0.0037.

## Using Community-Based Research Methods to Design Cancer Patient Navigation Training

Kathryn L. Braun, DrPH<sup>1,2</sup>, Amanda Allison<sup>1</sup>, and JoAnn U. Tsark, MPH<sup>1</sup>

<sup>1</sup>Imi Hale Native Hawaiian Cancer Network, Papa Ola Lōkahi, Honolulu, HI

<sup>2</sup>Office of Public Health Studies, John A. Burns School of Medicine, University of Hawai`i at Mānoa, Honolulu, HI

### Abstract

**Background**—Cancer mortality continues to be higher in Native Hawaiians than Whites, and research has identified numerous barriers to good cancer care. Cancer navigator programs provide individualized assistance to patients and family members to overcome barriers, promoting early diagnosis and timely and complete treatment.

**Objectives**—Our purpose was to design a training curriculum to provide community-based outreach workers serving Native Hawaiians with cancer patient navigator skills.

**Methods**—The *Ho`okele i ke Ola* (Navigating to Health) curriculum was informed by data gathered from Native Hawaiian cancer patients and their family members, outreach workers in Native Hawaiian communities, and cancer care providers. Based on findings, the 48-hour curriculum focused on cancer knowledge, cancer resources, and cancer communications. Three versions were developed: 1) 6 days of training and on-site tours in urban Honolulu; 2) 4 days of training on a neighbor island, with 2 days of on-site tours in Honolulu; and 3) a 3-credit community college independent study course. Graduates were interviewed after each session and 3 months after graduation about application of navigation skills.

**Results**—In 18 months, 62 health workers from community-based, clinical and community college settings were trained—31 in Honolulu-based trainings, 29 in neighbor island trainings where earlier graduates served as co-faculty, and 2 through Maui Community College. Follow-up data suggest increased knowledge, skills, capacity, and feelings of competence among trainees.

**Conclusions**—All three versions of the *Ho`okele i ke Ola* curriculum, developed with community input, have proven successful in increasing cancer patient navigation skills of trainees.

### Keywords

access to health care; cancer patient navigation; case management; community health aides; oncology; Pacific Islander Americans; utilization

### Background

Native Hawaiians are individuals who trace their ancestry directly to the Polynesians who peopled and governed the Hawaiian archipelago prior to the arrival of Westerners in 1778. Today, Native Hawaiians (race alone or in combination) comprise about 20% of Hawai`i's population, along with Caucasians (24%), Japanese (17%), Filipinos (14%), and people of

other ethnicities, mostly Asian and Pacific Islander.<sup>1</sup> Seven islands in the archipelago—O`ahu, Hawai`i, Maui, Kaua`i, Ni`ihau, Moloka`i, and Lâna`i—support human habitation. The capital, Honolulu, is on O`ahu. While the majority of Native Hawaiians live in urban and suburban areas, they are overrepresented in rural communities on O`ahu and the neighbor islands. Similar to indigenous and minority groups in other locales, Native Hawaiians have lower life expectancy and poorer health indicators than the other major ethnic groups in the state.<sup>2-5</sup> National data suggest that Native Hawaiians and other PIs have significantly worse cause-specific survival than non-Hispanic whites for most cancer sites.<sup>6-8</sup> Hawai`i data from 2006 suggest that only 88.2% of Hawaiian women 40 and older ever had a mammogram (vs. 93.1% of Caucasian women); only 42.4% ever had a sigmoidoscopy or colonoscopy (vs. 57.1% of Caucasians); and 23.3% of Hawaiians smoked (vs. 11.9% of Caucasians).<sup>9</sup>

Like other indigenous and minority Americans, Native Hawaiians face other barriers to timely cancer diagnosis and treatment. These barriers include lack of knowledge, poverty, lack of insurance, lack of access, and fear, as well as cultural barriers in the system and complacency in standard medical care.<sup>5-10-12</sup> The state's geography also presents challenges, as the bulk of cancer care resources are centered in Honolulu. Most neighbor island cancer patients must travel to Honolulu for diagnosis and treatment. Neighbor islanders treated in Honolulu must make frequent trips there or choose to relocate temporarily to Honolulu; both options impose financial, physical, and mental stress.<sup>11</sup> From focus groups conducted by `Imi Hale in 2000, we also knew that Native Hawaiians who survivor cancer are much like survivors of any ethnicity, e.g., they have pro-active health seeking behaviors, health insurance, and resources (money, family, education) that help them access the care they need in a timely manner.<sup>11</sup>

Cancer patient navigators provide individualized assistance to patients and family members to overcome these and other barriers, promoting early diagnosis and timely and complete treatment.<sup>12-22</sup> The first cancer patient navigation program was hospital-based, established at Harlem Hospital Center in New York City in 1990.<sup>12</sup> A community-based navigation program was developed by Native American Cancer Research (NACR) in Colorado in the mid-1990s to assist Native American women through breast screening.<sup>13-15</sup> Since then, many other cancer patient navigation programs have been developed and tested.<sup>16</sup> Findings from program evaluation and randomized controlled trials suggest that navigation is appreciated by patients and that navigated patients are more likely to receive timely screening and follow-through with diagnostic tests than non-navigated patients.<sup>17-19</sup> Currently, both the National Cancer Institute (NCI) and the Centers for Medicare and Medicaid Services (CMS) are testing cancer patient navigation to determine if it increases the timeliness of cancer diagnosis and the successful treatment/resolution of cancers that are diagnosed.<sup>21-22</sup> CMS is also investigating cost-savings associated with cancer patient navigation, and both research programs are examining differences in navigation services provided by different types of providers (e.g., nurses, social workers, and community outreach workers) using different approaches (e.g., face-to-face, telephone, and/or web) in different types of settings (e.g., hospital, clinic, and community).

In addition to curricula developed by grantees cited above, curricula to train cancer navigators have been developed by others, including Pfizer<sup>23</sup> and Cancer Care Nova Scotia.<sup>24</sup> The Community College of Denver (among others) offers courses for community outreach workers that include components useful for cancer patients navigation.<sup>25</sup> Taking a slightly different approach, the Lance Armstrong Foundation developed a cancer navigation manual that guides cancer patients to better navigate themselves.<sup>26</sup> Although each curriculum differs, most provide basic information on cancer, contact information for resource agencies, and guidelines on communicating with cancer patients and healthcare providers.

As part of our efforts to reduce cancer health disparities experienced by Native Hawaiians, the `Imi Hale - Native Hawaiian Cancer Network (`Imi Hale) conducted community-based research to develop and test a cancer patient navigation curriculum. `Imi Hale is one of 25 Community Network Programs (CNP) funded by the NCI's Center to Reduce Cancer Health Disparities.<sup>27</sup> It is a program of Papa Ola Lokahi (POL), a community-based agency dedicated to improving the health and wellness of Native Hawaiians. `Imi Hale collaborates with the five Native Hawaiian Health Care Systems (NHHCS), which provide health education and access services to approximately 25,000 individuals annually, the majority of whom are Native Hawaiian, on Hawai`i's seven inhabited islands. `Imi Hale also collaborates with more than 50 local and national partners (e.g., educational institutions, medical centers, non-profit organizations, and cancer care providers) to meet its mission.

Specific to the NHHCS, `Imi Hale subcontracts with each of the five systems, providing salary support for community outreach staff that focus on cancer. `Imi Hale also provides NHHCS outreach staff with training opportunities in cancer care, materials development, grant writing, and public speaking. In fact, these outreach staff had asked `Imi Hale to help them build skills to better navigate their clients with cancer. In response, `Imi Hale successfully sought funds from the Office of Hawaiian Affairs, a quasi-state agency in Hawai`i, for this project.

*'Imi Hale's* work is guided by principles of community-based participatory research (CBPR) and empowerment theory, both aimed at strengthening individual competence and community capacity to identify and resolve community problems.<sup>28-29</sup> In operationalizing these principles, we gathered data from Native Hawaiian cancer patients and family members, as well as providers that served them, to learn about cancer care barriers and to identify needed knowledge and skills for navigators. Findings were incorporated into the curriculum. Technical assistance was provided by a seasoned cancer patient navigator from NACR in Colorado. The result was the development of three versions of our own curriculum: 1) 6 days of training and on-site facility tours in urban Honolulu, 2) 4 days of training on a neighbor island, followed by 2 days of on-site facility tours in Honolulu, and 3) a 3-credit community college course. The fluidity of the curricula accommodated different cohorts, training needs and settings. A total of five trainings have been completed to date.

In this paper, we outline how we used CBPR methods to develop the curriculum, we describe the curriculum, and we share findings from our preliminary evaluation of the trainings.

## Developing the Curriculum

In developing the curriculum, we talked with 5 NHHCS outreach staff, we held discussion groups with cancer survivors and family members on five islands, we interviewed 20 cancer care providers in Honolulu, we surveyed 200 outreach workers and cancer care providers across the state, and we sought technical assistance from the NACR cancer navigator program in Colorado (Table 1).

## Discussion with NHHCS Outreach Staff

We invited a representative from each of the five NHHCS to Honolulu to discuss their request for training in helping their clients with cancer. We shared information about the concept of cancer patient navigation as practiced in the continental US and asked if it sounded like something that might be useful in Hawai`i. Outreach staff said that they already "navigated" their clients to medical and social service resources, but they had difficulty navigating cancer patients because of the complexity of cancer services and the centralization of cancer care in urban Honolulu.

Beyond basic screening tests, they did not know how cancer was diagnosed or treatment regimes decided upon. They welcomed the opportunity to learn more about cancer, resources, and effective ways to work with clients with cancer. They requested opportunities to tour cancer treatment facilities and meet the providers that their clients with cancer might encounter. Following traditional Hawaiian teaching-learning methods, they wanted to observe in the first training, to apply what they learned in their respective NHHCS, and then organize and co-teach training for other community outreach workers at their NHHCS.<sup>30</sup> Because they were employed by different NHHCS, they did not want standardized reporting forms but wanted to learn how to help their clients keep their own cancer records. We told them that time commitment for navigator training in other locales ranged from 3 days to 480 hours.<sup>31</sup> Given that these outreach workers were full-time employees of five different NHHCS and had numerous responsibilities besides cancer navigation (e.g., managing tobacco cessation, exercise, nutrition, and/or cancer screening programs), they felt that 4 to 6 days of training would be most manageable. They also suggested we join them in listening to their clients with cancer about the barriers encountered.

### Discussions with Clients

NHHCS outreach workers organized discussion groups with their clients with cancer to learn about their cancer care experiences. Our design for these groups was informed by our successful discussions with Native Hawaiian cancer survivors in 2000, to which survivors and family members were invited to “share their stories.”<sup>11</sup> In both cases, the NHHCS had free reign to identify participants, and cancer patients and family members were interviewed together.

Altogether, 45 individuals (29 cancer patients and 16 family members) participated in seven discussion groups on five islands. Prior to the two-hour discussion group, participants completed informed consent forms. As in the 2000 discussion groups, we asked each cancer survivor and family member to “tell his/her story.” They were prompted to identify things and/or people that helped or hindered them in the discovery, treatment, and recovery phases of their care. They also were asked to speculate on the kinds of support that might have made their care process easier or better. Responses were recorded on a newsprint and notepaper; notes from both sources were transcribed and analyzed. Lists were produced identifying barriers to care and desired supports.

From these discussion groups with Native Hawaiian cancer patients and families, we learned that cancer still is viewed by many as a death sentence, and that anxiety was heightened by all the waiting, e.g., for the doctor, for the definitive diagnosis, for the treatment plan, for services. Doctors tended to provide patients with a menu of options rather than clear direction, and patients did not feel they had enough information to make good choices. Costs, insurance, lack of providers, and burdens associated with traveling to Honolulu often dictated treatment decisions. Patients with support reported doing better than patients without support; family members and outreach workers were preferred as sources of support. Patients and families wanted a navigator that could help them learn about cancer, access insurance and services, maximize support networks, and feel more in control of the situation. Some expressed a reluctance to burden others with their questions and wanted a navigator who understood their barriers and addressed them without making the patient feel stupid or burdensome.

### Key Informant Interviews

Using a snow-ball sampling method, we interviewed 20 cancer care professionals as key informants, including physicians, nurses, social workers, and educators. These professionals and the institutions they represented were already, or became, partners with Imi Hale during this process. We informed them about our goal to train cancer patient navigators, asked them

about barriers to cancer care, particularly for Native Hawaiians, and asked what knowledge and skills patient navigators should have to help Native Hawaiians overcome these barriers.

Interviews lasted an average of an hour. Themes were summarized from written notes taken during the interview and organized into two types of barriers. Access barriers were defined as barriers encountered by patients in accessing screening, getting a definitive cancer diagnosis, and getting treatment. Systems barriers were defined as barriers that patients encountered in following through with cancer treatment recommendations. Leading access barriers included: the high cost of care, co-pay, and/or medications; lack of insurance or underinsurance; lack of physicians, specialists, and second opinions; distance from screening and treatment facilities; time and cost of transportation; and difficulty seeking care when too busy with other obligations (e.g., working and care giving). The most prevalent systems' barriers included the need to run around between providers, offices, and facilities in the course of diagnosis and treatment; lack of coordination within the cancer-care system; not knowing who is in charge, not knowing which questions to ask; feelings of intimidation; insensitivity and poor communication on the part of providers; providers' lack of knowledge of/referral to other resources; and lost referrals and paperwork.

Key informants were enthusiastic about `Imi Hale's development of cancer patient navigation training, and almost all agreed to serve as co-faculty and/or arrange tours of their cancer care facility once training was organized. They felt the curriculum should include three major areas--cancer knowledge, cancer resources, and cancer communications. Regarding cancer knowledge, they felt navigators should know about the major diagnostic tests, treatments, and impacts of common cancers, and understand about clinical trials, treatment side effects, nutritional issues, psychological issues, and end-of-life options. Given the complexity and ever-changing nature of cancer care, they felt that navigators needed to build skills in finding answers to emerging questions. Knowledge of resources available to cancer patients was considered critical, including informational, medical, social, and financial resources. Related to communication, navigators needed to know how to define and communicate their role, and to maintain confidentiality. We also learned that The Queen's Medical Center (QMC, the largest cancer-care provider in Honolulu) was starting a hospital-based navigation program, and we invited their newly hired navigators to participate in our training.

### Key Informant Survey

A health-provider survey was developed incorporating themes drawn from discussion groups and key informant interviews. Surveys were mailed to 200 health providers that we knew were working with Native Hawaiians and/or in cancer care, including physicians, nurses, outreach workers, and others. Respondents received only one mailing, and 86 completed surveys (43%) were returned. Respondents were asked if they were interested in participating in a cancer navigation training and, if so, to answer additional questions about preferences for training delivery. Frequencies were calculated using SPSS.

Survey findings confirmed the perceptions of the key informants, as well as the research literature, about the barriers facing our cancer patients (Table 2). However, the survey added to our knowledge about demand for and preferences for training. Of 86 respondents, 50 indicated that they would like to participate in future trainings, and the majority of them wanted trainings to be provided during the workday (rather than evenings or weekends), to be provided over several weeks (e.g., 1–2 days a week for 3–6 weeks), to be offered on the neighbor islands, and to carry community college credits. In terms of content, 100% wanted to tour medical facilities and meet cancer care providers, 90% wanted skills in communicating with cancer patients and providers, and 82% wanted more information on cancer diagnosis and treatment.



## Technical Assistance

At the end of the data gathering phase, `Imi Hale sought technical assistance and mentoring from NACR because of their experience with patient navigation in American Indian communities that face similar challenges in accessing and accepting timely cancer care. At an all-day meeting with NACR staff and NHHCS community outreach staff, we developed a tentative agenda for a multi-day navigator training. We also agreed on a list of “dos” and “don’ts” for our community-based Native Hawaiian navigators (Table 3). For example, we decided that NHHCS navigators would help patients get information about their diagnosis and care, but not make medical decisions, and that our navigators would help families re-negotiate roles to meet patient needs, but do not replace family or solve family disputes. The consultant visit culminated in a reception designed to thank and share findings with everyone that had participated in our data-gathering phase. About 70 individuals attended the reception at which they learned more about the NACR navigator model, received a summary of our findings, and reviewed our draft curriculum.

## Unique Features of the Curriculum

Research findings and technical assistance led to the development of a 48-hour curriculum called *Ho`okele i ke Ola*, which means Navigating to Health. Our training is unique to those offered on the US continent in four ways. First, we developed 3 versions of the training to accommodate the diverse needs of community outreach workers on different islands: 1) 6 days of training and tours in urban Honolulu; 2) 4 days of training on a neighbor island, with 2 days of tours in Honolulu; and 3) a 3-credit community college independent study course. Second, we maximized opportunities to build relationships between community outreach workers and hospital-based providers by inviting both to the training. For example, newly hired navigators from the Moloka`i-based CMS navigator program and from QMC participated in the first training, along with 1 to 2 representatives from each NHHCS. On Neighbor Islands, organizers invited hospice, a private case management group, and the American Cancer Society (ACS) to send staff or volunteers to trainings. The bonds created among the trainees ultimately increased continuity of care for cancer patients, especially the bond created between navigators in the NHHCS and the hospitals. Third, NHHCS graduates of the first navigator training became co-teachers of subsequent training offered on their own islands. This helped build their capacity in cancer care as they identified potential trainees, faculty, and tour sites on their islands, and participated as lecturers.

Fourth, for all three versions, the curriculum was organized around 14 learning objectives (Table 4), and materials were transmitted through lecture and active learning activities. The latter included experiential exercises, role playing, video viewing, tours, demonstrations, short writing assignments, case studies, story-telling, discussion, and networking opportunities. These active strategies responded to community demand and are recommended by adult learning theory to accommodate variations in learning style.<sup>32–33</sup> For example, to cover the learning objective about identifying the unique diagnostic tests, treatments, and impacts of nine types of cancer, students received lectures from providers (or viewed PowerPoint lectures or videos on WebCT), toured relevant cancer diagnostic and treatment facilities, “talked story” with cancer patients and families, and completed worksheets on specific cancers. One module focused on compiling and organizing a cancer navigation resource binder. Students collected education materials and listed resource people that could help them with future cancer navigation questions. For the community college independent study course, the binder was their final graded activity. All students demonstrated their ability to help patients by working through mock cancer cases to identify barriers, informational needs, and appropriate resources. These case plans could be completed individually and discussed or role played by small groups.

## Delivery and Testing the Curriculum

The first two trainings were offered in Honolulu--August-September 2006, and March-April 2007. Neighbor island trainings were provided on Maui in June 2007 (with Honolulu tours in August 2007), and on the island of Hawai'i in November 2007 (with Honolulu tours in February 2008). As noted above, graduates of the first Honolulu training organized neighbor-island site trainings and served as co-faculty. The curriculum was converted into a three-credit independent study course and offered by the nursing department at Maui Community College (MCC) in fall 2007. Over 18 months, 62 health professionals and paraprofessionals (including 28 community outreach workers) have been trained—31 in Honolulu-based trainings, 29 in neighbor island-based training, and 2 through MCC.

In the first training, participants completed 6 pre-post tests, one for each day of training (although tests for Days 4 and 5 were combined). Tests included 10-short-answer items exploring knowledge of cancer, screening, and resources. As shown in Table 5, post-test scores were higher than pre-test scores on all tests, improving from 7.57 to 8.43 on Day 1 (navigator roles and Cancer 101), from 5.92 to 8.15 on Day 2 (informational and community-based resources), from 7.14 to 9.07 on Day 3 (female cancers, treatments, and side-effects), from 11.42 to 15.33 on Days 4 and 5 (other cancers, treatments, and side-effects), and from 7.75 to 8.92 on Day 6 (hospice and palliative care). Although these findings suggested that participants gained knowledge, trainees complained that tests were distracting and did not capture their learning.

Thus, in subsequent Honolulu and Neighbor Island trainings, we asked participants to write answers to a series of open-ended questions about what they had learned each day and how this could be used in their jobs. Most trainees were required to provide this information to their supervisors, so the self-evaluation reports served two purposes. The 3-credit independent study college course was evaluated by grading the quality of the assignments completed by the students, including a resource binder for their use in navigating patients.

For all variations of the training curriculum, time was spent in the last session to evaluate learning as well as the curriculum. To evaluate learning, trainees were given case studies of cancer patients and asked to describe how they could help each one, drawing from the skills and knowledge learned from the training. Those working with clients also were to describe a case that they themselves had navigated since training began. To evaluate the curriculum, trainees were then asked to identify what they liked best about the training and ways it could be improved. Finally, they were asked about perceived needs for continuing education.

In evaluations of all three versions of the curriculum, 100% of trainees demonstrated that they could apply new knowledge and skills by describing how they would resolve a case study. About 80% of trainees described a case that they themselves had navigated since training began, demonstrating increased knowledge, skills, and networks to help patients. For example, one navigator reported, "I got 3 referrals this week...I provided information and support, and linked them to the resources they need." Another said, "I helped the family figure out who would pick up the kids and who would make dinner while mom was going through chemo." Another said: "The connection with [the navigator] at the medical center has been invaluable. I trust her to navigate the hospital care, and she trusts me to arrange things back in the community." The 2 MCC students both did well on assignments and developed comprehensive resource binders for themselves.

Trainees liked the on-site facilities tours and networking aspects of the training best. They reported feeling enriched by meeting cancer care providers, learning directly from physicians and nurses about treatment, learning medical terminology, seeing the technology (pathology slides, colonoscope, mammography machine, radiation therapy equipment, chemotherapy

room, etc.), hearing from cancer patients and families, touring the hospitals (including cancer services, rooms, hallways, parking, gift shop, cafeteria, etc.), learning to access cancer information by phone and Web, and getting to know the other trainees and the healthcare providers. Trainees identified needs for continuing education in other types of cancer, financial assistance for patients, case management, and staying healthy themselves as navigators.

## Discussion

Our curriculum focused on three areas—cancer knowledge, services, and communications—because our community-based research suggested that lack of knowledge and access (especially for Neighbor Island patients) were critical barriers to care (rather than cultural beliefs or attitudes regarding cancer and health care). The training was designed for community-based navigators working with Native Hawaiians, but others were invited to participate, including hospital-based navigators, ACS volunteers, hospice workers, social workers, case managers, and nurses in both community and clinical settings. Although some of the information about cancer or case management might have seemed elementary to those trainees who also had nursing and social work degrees, their participation in training with community outreach workers served to build relationships between the navigators with various educational backgrounds and working in various settings. We realize the ultimate duties of a specific navigator will depend on his/her academic training and licensure, as well as the setting in which he/she is employed. But cancer patients cross from the community to hospital and back again, so navigators in both settings need to know each other. While hospital-based navigators concentrate on getting Native Hawaiian patients through their medical care system, they rely on navigators from the NHHCS to help patients get information and to arrange services and support in their own communities.

Because learning objectives are achieved through a variety of teaching methods (lecture, web-based PowerPoint, tours, interviews, worksheets, writing, etc), the curriculum has built-in redundancy. Organizers can choose which combination of lectures and activities will best meet the learning objectives. Having more materials than needed also allows each training or community college offering to be tailored to the audience and the availability of faculty. For example, a web lecture and worksheet on genetics and genetic counseling are available. The nursing instructor at the community college found these materials relevant for her students because the genetic determinants of colorectal cancer were stressed in the web lecture and she felt that nursing students needed to be cognizant of the role of genetic counseling in cancer. However, in the face-to-face trainings, the lecture on colorectal cancer was provided by a physician during a medical center visit/tour, and the genetic determinants of colorectal cancer were not discussed.

Another instructor at MCC will be adapting the course as an elective for MCC's department of health and social services, with plans to offer it in fall 2008. It is expected that she will add to the materials available for future offerings of the training. The community college course materials also are being used to train individuals who need to learn about cancer patient navigation but cannot attend a face-to-face training. For example, a navigator recently hired by a local medical center is being guided through the community college curriculum in the first month of her hire. She also will be invited to the next face-to-face training, which will serve as a good review and enhance her network of clinical and community contacts.

Based on findings, we believe that *Ho`okele i ke Ola* has been successfully in providing a good foundation in cancer patient navigation. However, all versions of the curriculum emphasize to students that they will not have "all the answers" about cancer at the end of the training. Rather, emphasis is on the necessity of knowing how to help patients/families identify questions they need to be asking and how to find answers. We found the graduates of the community college



course to be more fluent with online resources, while the graduates of the in-person training more apt to rely on the many contacts and relationships they made through tours and guest speakers to help them find answers. Recognizing the advantages of both, all versions of the curricula teach and encourage both online and people-oriented fact finding.

A weakness of our project was our evolving evaluation methods. Although it is possible to ask trainees to complete pre-post-tests of knowledge, trainees did not see that this measured their learning. Because trainees were able to demonstrate their enhanced skills by working through case studies and relating ways that they used training information in patient care, we are working on ways to systematically document these improvements. To do this, we will pilot performance checklists developed by Denver Community College in our next training.<sup>25</sup>

To date, the *Ho`okele i ke Ola* curriculum has been used as a supplement to on-the-job and/or academic training. Additionally, we have had a few family caregivers take the training, and they also were able to identify ways in which the training helped them better assist a loved one with cancer. However, we are learning that trainees need access to continuing education, which allows navigators to work through difficult cases, expand their skills, and build camaraderie. Concurrently, health institutions and insurers are demonstrating greater awareness of and interest in patient navigation and its role in the menu of services for cancer patients. `Imi Hale will continue to help develop this discipline and help prepare our graduates for cancer navigator certification, should one be developed. The establishment of standards and testing mechanisms for such a certification may become necessary in the future, and the findings from national studies by CMS and NCI, as well as findings from regional navigator programs, will help inform the further development of this health role.

## Acknowledgments

This project was supported by a grant from the Office of Hawaiian Affairs and a research supplement from the National Cancer Institute 3 U01 CA114630-02S1 to increase the diversity in health-related research. We thank Ka`ohimānu Lydia Dang, BA, BS for her help with this project. An earlier version of this paper was presented at the American Public Health Association 135<sup>th</sup> Annual Meeting in Washington DC, November 2007.

## References

1. Department of Business, Economic Development and Tourism. The State of Hawaii data book 2006. available at <http://hawaii.gov/dbedt/info/economic/databook/db2006/>
2. Braun K, Yang H, Onaka A, Horiuchi B. Life and death in Hawai`i: ethnic variations in mortality and life expectancy. *Hawaii Med J* 1996;55:278–83. 302. [PubMed: 9009460]
3. Johnson DB, Oyama N, LeMarchand L, Wilkens L. Native Hawaiians mortality, morbidity and lifestyle: comparing data from 1982, 1990 and 2000. *Pacific Health Dialog* 2004;11(2):120–30. [PubMed: 16281689]
4. Office of Hawaiian Affairs. Honolulu, HI: Author; 2006 Native Hawaiian data book. Available at <http://www.oha.org/pdf/databook/2006/DataBook2006Health.pdf>
5. Freeman HP, Chu KC. Determinants of cancer disparities: barriers to cancer screening, diagnosis, and treatment. *Surg Oncol Clin N Am* 2005 Oct;14(4):655–69. [PubMed: 16226685]
6. American Cancer Society, Cancer Research Center of Hawai`i, and Hawai`i Department of Health. Hawai`i cancer facts & figures: 2003–2004. Honolulu, HI: Authors; Available at <http://www.crch.org/Cancer0304.pdf>
7. Goggins WB, Wong GKC. Poor survival for US Pacific Islander cancer patients: evidence from the Surveillance, Epidemiology, and EndResults database: 1991 to 2004. *J Clin Oncol* 2007;25:5738–5741. [PubMed: 18089868]
8. Miller BA, Chu KC, Hankey BF, Ries LA. Cancer incidence and mortality patterns among specific Asian and Pacific Islander populations in the US. *Cancer Causes Control* 2008;19:277–256.

9. Hawai'i Department of Health. Behavioral Risk Factor Surveillance System. Honolulu, HI: Author; Available at <http://hawaii.gov/health/statistics/brfss/brfss2006/demo06.html>
10. Tsark JU. Cancer in Native Hawaiians. *Pacific Health Dialogue* 1998;5:315–327.
11. Braun KL, Mokuau N, Hunt GH, Kaanoi M, Gotay CC. Supports and obstacles to cancer survival for Hawaii's native people. *Cancer Pract* 2002;10:192–200. [PubMed: 12100103]
12. Freeman HP, Muth BJ, Kerner JF. Expanding access to cancer screening and clinical follow-up among the medically underserved. *Cancer Pract* 1995;3:19–30. [PubMed: 7704057]
13. Burhansstipanov L, Wound DB, Capelouto N, Goldfarb F, Harjo L, Hatathlie L, Vigil W, White M. Culturally relevant “navigator” patient support: The Native Sisters. *Cancer Pract* 1998;6:191–194. [PubMed: 9652252]
14. Dignan MB, Burhansstipanov L, Hariton J, Harjo L, Rattler T, Lee R, Mason M. Comparison of two Native American navigator formats: Face-to-face and telephone. *Cancer Control* 2005;12(Supple 2): 28–33. [PubMed: 16327748]
15. Native American Cancer Research. Lakewood, CO: Author; 2007. *Get on the Path*. Available at <http://www.natamcancer.org>
16. Dohan D, Schrag D. Using navigators to improve care of underserved patients: current practices and approaches. *Cancer* 2005 Aug 15;104(4):848–55. [PubMed: 16010658]
17. Steinberg ML, Fremont A, Khan DC, Huang D, Knapp H, Karaman D, Forge N, Andre K, Chaiken LM, Streeter OE Jr. Lay patient navigator program implementation for equal access to cancer care and clinical trials: essential steps and initial challenges. *Cancer* 2006 Dec 1;107(11):2669–77. [PubMed: 17078056]
18. Battaglia TA, Roloff K, Posner MA, Freund KM. Improving follow-up to abnormal breast cancer screening in an urban population. A patient navigation intervention. *Cancer* 2007 Jan 15;109(2 Suppl):359–67. [PubMed: 17123275]
19. Ell K, Vourlekis B, Lee PJ, Xie B. Patient navigation and case management following an abnormal mammogram: a randomized clinical trial. *Prev Med* 2007;44:26–33. [PubMed: 16962652]
20. Ferrante JM, Chen PH, Kim S. The effect of patient navigation on time to diagnosis, anxiety, and satisfaction in urban minority women with abnormal mammograms: a randomized controlled trial. *J Urban Health* 2008;85:114–24. [PubMed: 17906931]
21. Center for Medicare and Medicaid Services. Cancer Prevention and Treatment Demonstration for Ethnic and Racial Minorities. 2006. Available at [http://www.cms.hhs.gov/DemoProjectsEvalRpts/downloads/CPTD\\_FactSheet.pdf](http://www.cms.hhs.gov/DemoProjectsEvalRpts/downloads/CPTD_FactSheet.pdf)
22. National Cancer Institute. Center to Reduce Cancer Health Disparities. Available at <http://crchd.cancer.gov>
23. Pfizer. New York, NY: Author; 2006. *Patient navigation in cancer care: Guiding patients to quality outcomes*. Available at <http://www.patientnavigation.com/public/program/>
24. Nova Scotia Cancer Patient Education Committee, Cancer Care Nova Scotia. *Navigating the system: A guide for patients, families and caregivers*. Halifax, Nova Scotia: Author; 2005.
25. Community College of Denver. Program Areas of Course Descriptions. Available at [www.ccd.edu/courseindex.aspx?CID=18](http://www.ccd.edu/courseindex.aspx?CID=18)
26. Lance Armstrong Foundation. *Resource for cancer survivors: Survivorship notebook*. Austin, TX: Author; 2004–2005.
27. Braun K, Tsark J, Santos L, Aitaoto N, Chong C. Building Native Hawaiian capacity in cancer research and programming: The legacy of *'Imi Hale*. *Cancer* 2006;107(8 Suppl):2082–90. [PubMed: 16977599]
28. Minkler, M.; Wallerstein, N., editors. *Community-Based Participatory Research for Health*. San Francisco, CA: Jossey-Bass; 2003.
29. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: Assessing partnership approaches to improve public health. *Ann Rev Public Health* 1998;19:173–202. [PubMed: 9611617]
30. Pukui, MK.; Haertig, EW.; Lee, C. *Nana i ke kumu (Look to the source)*. Honolulu, HI: The Queen Lili'uokalani Children's Center; 1972.
31. Personal Communication, Margorie Kagawa-Singer and Sora Park-Tanjisiri, September 19, 2006.

32. Cranton, P. Understanding and promoting transformative learning: a guide for educators for adults. San Francisco: Jossey-Bass Publishers; 1994.
33. Kolb, David A. Experiential learning: experience as the source of learning and development. Prentice-Hall, Inc; Englewood Cliffs, N.J: 1984.

**Table 1**

## Participants in Data-Gathering Activities

Activity	Participants
Discussion with NHHCS outreach staff	Five community outreach workers, one each of five Native Hawaiian Health Care Systems (NHHCS), serving approximately 20,000 individuals (mostly Native Hawaiian) on the state's 7 inhabited islands.
Discussions with cancer survivors and family members on five islands,	45 individuals (29 cancer patients and 16 family members) in seven discussion groups on five islands, organized by community outreach staff at the NHHCS.
Key informant Interviews	20 cancer care providers in Honolulu, including physicians, nurses, social workers, and educators, who were already, or Became, partners with 'Imi Hale.
Key informant survey	200 cancer care providers (including physicians, nurses, outreach workers, and others) were mailed surveys. 86 (43%) responded, including 50 that indicated that they would like to participate in a future cancer patient navigation training.
Technical assistance	One cancer patient navigator from Native American Cancer Research in Colorado.
Report back to Participants	70 individuals who had participated in discussion groups, interviews, and/or survey attended reception to receive summary of findings and review draft of curriculum.

**Table 2**

Top Barriers to Care for Native Hawaiian Cancer Patients, Identified through the Key Informant Survey

	Frequently experienced	Sometimes Experienced
<b>Access-to-Care Barriers</b>		
• High cost of care, co-pay, and/or medications	68 (80%)	14 (16%)
• Lack of insurance or under-insurance	46 (54%)	26 (31%)
• Lack of physicians, specialists, second opinions	26 (31%)	37 (43%)
• Distance from facility; time and cost of transportation	49 (58%)	27 (32%)
• Too busy with other obligations to seek care	31 (36%)	38 (45%)
<b>Cancer-Care-Systems Barriers</b>		
• Not knowing what to ask	56 (66%)	26 (31%)
• Need to run around between providers, offices, facilities	50 (59%)	26 (31%)
• Lack of coordination within the cancer-care system	37 (44%)	35 (42%)
• Not knowing who is in charge	33 (39%)	26 (31%)
• Feelings of intimidation	51 (60%)	24 (28%)
• Insensitivity/poor communication on the part of providers	33 (39%)	43 (51%)
• Providers' lack of knowledge of/referral to other resources	17 (20%)	27 (32%)
• Lost referrals, lost paperwork, mixed up x-rays, etc	14 (16%)	39 (46%)



**Table 3**Cancer Patient Navigator Roles as Defined by the *Ho`okele i ke Ola Curriculum*

In general, Cancer Patient Navigators...	
Do:	Don't:
<ul style="list-style-type: none"> <li>• Help patients get information they need about their diagnosis and care</li> <li>• Help patients get what they need; refer to available resources</li> <li>• Help families re-negotiate roles</li> <li>• Coordinate appointments</li> <li>• Help patients keep a record of care</li> </ul>	<ul style="list-style-type: none"> <li>• Make medical decisions</li> <li>• Pay for housing, food, transport or Childcare</li> <li>• Take the place of the family; solve domestic disputes</li> <li>• Pay for treatment</li> <li>• Keep patients' medical records</li> </ul>

**Table 4**

## Training Content Areas and Delivery Methods

Learning Objective	Teaching Methods
1. Describe the role of a Cancer Patient Navigator	L •View lecture on cancer patient navigation: definition and role CA •Talk story with a patient navigator W •Write about new knowledge/skills and how they can be applied in your work (after each day) CA •Give examples of how knowledge/skills have been applied (end of last class)
2. Explain the importance of confidentiality.	L •View lecture on confidentiality and HIPAA L •View lecture on culture and communication CA •Discuss personal culture and communication styles
3. Describe barriers to cancer care and ways to overcome them	L •View lecture on cancer patient navigation: definition and role CA •Discuss beliefs that can limit help seeking W •Write how to overcome specific barriers
4. Identify unique tests and treatments of cancer. (focus on 8 types)	L •View lecture on cancer 101 L •Receive information on specific cancers from providers during facility Tours T •Tour cancer diagnostic and treatment facilities, including treatment rooms and equipment CA •Talk story with cancer patients and their families W •Complete worksheets on specific cancers, including sections on medical, social, and psychological issues for patient cases. RB •Add to resource binder
5. Identify related physical, psychological and social issues likely to face people with cancer and their Families	L •View lecture on psychological issues for patients, families, and Navigators CA •Talk story with cancer patients and their families W •Search Web and complete worksheet on side-effects and nutritional issues of treatment RB •Add to resource binder CA •Use "100s of Questions" booklet to identify questions the patient should ask
6. Demonstrate the ability to gather Data and put it into a "Patient Record".	L •View lecture on types of information a patient should keep CA •Review a model of a record the patient may want to keep RB •Find and review free resources for patient record keeping, add to resource binder
7. Find reliable cancer info from agencies and on the Web.	CA •Explore the website for the Cancer Information Services (CIS) W •Find the answers to these cancer questions online and by phone NL •Lunch with CIS and American Cancer Society (ACS) staff. RB •Add to resource binder.
8. Describe cancer- related services available in your community.	T •Tour of cancer diagnostic and treatment facilities L •View lecture on financial services, including pharmaceutical assistance programs NL •Lunch with CIS, ACS, and other providers of cancer care. W •Develop resource list for a specific cancer patient case. RB •Add to resource binder.

Learning Objective	Teaching Methods	
9. List advantages of participating in clinical trials and barriers to participation.	L T CA NL RB	<ul style="list-style-type: none"> <li>•View lecture on clinical trials: advantages and barriers</li> <li>•Tours of facilities and agencies connected with clinical trials</li> <li>•Talk story with patient who benefitted from clinical trial</li> <li>•Lunch with clinical trials network</li> <li>•Add to resource binder.</li> </ul>
10. Define palliative care and hospice care.	L T NL RB	<ul style="list-style-type: none"> <li>•View lecture on palliative care and hospice</li> <li>•Tour of facilities that provide hospice and/or palliative care</li> <li>•Lunch with palliative care network</li> <li>•Add to resource binder.</li> </ul>
11. Complete an Advance directive.	L W CA	<ul style="list-style-type: none"> <li>•View lecture on advance directives and end of life issues</li> <li>•Complete an advance directive for oneself</li> <li>•Discuss feelings associated with talking about the end of life</li> </ul>
12. Demonstrate the ability to work Through “mock” cancer cases.	L CA W	<ul style="list-style-type: none"> <li>•View lecture on case management</li> <li>•Work through cancer cases to practice identifying barriers and information/resource needs; these can be completed individually or discussed and/or role played by small groups.</li> </ul>
13. Organize a Resource binder	RB	<ul style="list-style-type: none"> <li>•The “resource binder” exercise is introduced on the first day of class, and a completed binder is due on the last day. Students take this binder to the worksite to use as a cancer patient navigator.</li> </ul>
14. Describe ways to care for Yourself	L CA	<ul style="list-style-type: none"> <li>•View lecture on burnout and grief</li> <li>•Participate in relaxation exercises</li> </ul>

L=lecture, CA=class activities, T=tours, NL=networking lunches, W=writing, RB=resource binder

**Table 5**

Mean Pre and Post-test Scores (n=14)

	Items	mean pretest score	mean post-test score	p value
Day 1	10	7.57	8.43	p = 0.04
Day 2	10	5.92	8.15	p = 0.003
Day 3	10	7.14	9.07	p = 0.003
Days 4 & 5	20	11.42	15.33	p = 0.001
Day 6	10	7.75	8.92	p = 0.142