Building Family Capacity for Native Hawaiian Women with Breast Cancer

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Native Hawaiian women have the highest breast cancer incidence and mortality rates when compared with other large ethnic groups in Hawai'i. Like other women, they rely on the support of their families as co-survivors. This project explored the feasibility and effects of a culturally tailored educational intervention designed to build family capacity by improving the knowledge and skills of the woman and her family in dealing with breast cancer, particularly in the latter stage of recovery care. Twenty-nine Native Hawaiian women with breast cancer, along with a close family member, were randomly assigned to the intervention (n = 15) or a wait-list control group (n = 14). The authors assessed the knowledge, self-efficacy, and coping skills of women and their family members and the recovery care behaviors of the women at baseline and at four months (after the intervention or control period). The intervention group made significant improvements in self-efficacy and coping; the wait-list control group did not. Evaluation of the intervention suggests that it was well received by participants. This work has relevance for social workers wanting to design and test culturally appropriate interventions for minority groups.

KEY WORDS: cancer; culturally tailored intervention; family support; Native Hawaiian

ative Hawaiians experience significant health and social disparities compared with other people in Hawai'i, including lower life expectancy, higher mortality from heart disease and cancer, and greater prevalence of poverty and homelessness (Office of Hawaiian Affairs, 2006; Park, Braun, Horiuchi, Tottori, & Onaka, 2009). In Hawai'i, Native Hawaiian women have the highest breast cancer incidence and mortality rates, and they are more often diagnosed in later stages of disease and at earlier ages (Hawai'i Cancer Facts and Figures, 2010). They also have more comorbid conditions-such as heart disease, hypertension, and diabetes-than women of other ethnicities and more risk factors for cancer, including obesity, tobacco use, and low levels of physical activity and consumption of produce (Maskarinec et al., 2006; Moy, Sallis, & David, 2010).

FAMILY SUPPORT

There is burgeoning literature on family and personal support that reinforces women's efforts to stay healthy after a cancer diagnosis (Baider, Cooper, & Kaplan De-Nour, 2000; Veach, Nicholas, & Barton, 2002). Much of this literature focuses

on acute care (Bloom, Stewart, Johnston, Banks, & Fobair, 2001; Lewis, 1986), even though it is acknowledged that family support is equally important during recovery care when stressors are chronic (Anderson, 2010; Manne, 1998). In later stages of cancer, families can become tired and overwhelmed in caring for their loved one, which erodes their ability to cope and provide effective support. The health care system has been criticized for its lack of attention to recovery care, a phase in the cancer trajectory that is critical to survivorship and long-term health (Institute of Medicine, 2005). Since 2006, breast cancer survivorship programs have been established to increase compliance with follow-up care and link women to support groups (Kaur et al., 2012). However, it is important that survivorship programs be tailored to the cultural groups they serve, especially to groups like Native Hawaiians and other Pacific Islanders who may not be reached by mainstream programs.

Native Hawaiian women experience their cancer in the context of their families. In focus groups with Native Hawaiian women cancer patients and their families, three needs were identified—access to information, assistance with

physical care, and emotional support (Braun, Mokuau, Hunt, Kaʻanoi, & Gotay, 2002). Families strived to provide the best level of care, although deficits in knowledge and lack of self-efficacy in accessing information managing the household, and communicating with health care providers presented obstacles to their capacity to cope and provide care. Although there is a growing body of materials and resources on family support, Native Hawaiian women cancer patients reported not using them.

CULTURAL TAILORING

Researchers who work with ethnic minorities recommend that interventions be tailored to take into account the surface structures and deep structures of the ethnic minority culture (Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2002; Resnicow, Baranowski, Ahluwalia, & Braithwaite, 1999). Surface structure refers to the external aspects of culture that can be reflected in intervention materials (such as brochures and curriculums), staffing, settings, and recruitment strategies. This structure attracts members of the target populations to the intervention, because materials and staff look familiar and the intervention is offered in a trusted setting. Deep structure refers to social, historical, environmental, and psychological forces that may influence behavior. Attending to deep structure, for example, by incorporating cultural values, increases the salience of the intervention. Culturally tailored programs that reflect surface and deep structures of Hawaiian culture have proven to be effective in increasing cancer screening among Native Hawaiians in Hawai'i (Braun, Fong, Ka'ano'i, Kamaka, & Gotay, 2005; Gellert, Braun, Starkey, & Morris, 2006; Ka'opua, Park, Ward, & Braun, 2011).

The experience of cancer in context of the family becomes unique for Native Hawaiian women when viewed from a cultural perspective. Native Hawaiian cancer patients highlighted the importance of cultural values and traditions in dealing with their cancer (Braun et al., 2002). Spirituality (ho 'omana) assumes a central role in Native Hawaiian culture. For many cancer patients, invoking the power of ancestral family spirits, as well as that of a Christian God, becomes significant in their healing. Responsibilities (kuleana) become more pronounced as family members collectively assume roles in support and

caregiving. Thus, for many Native Hawaiians, it is important to consider strategies to increase family capacity that incorporate cultural values and practices.

PREVIOUS RESEARCH AND SPECIFIC AIMS

This research study built on a pilot study of a culturally tailored intervention for Native Hawaiian breast cancer survivors and their families. In the pilot, six Native Hawaiian women and their 10 family members in the intervention group made greater improvements in self-efficacy and coping skills than did the four Native Hawaiian and eight family members in the control group. This previous work produced results that began to establish the feasibility and effectiveness of the intervention, but there were limitations related to recruitment, sample size, intervention protocol, and measures (Mokuau, Braun, Wong, Higuchi, & Gotay, 2008). In the current study, we sought to measure the impact of the intervention (refined based on findings from the pilot) on a larger sample and to track success of our recruitment and retention strategies, intervention protocol, and the measures. Specifically, we hypothesized that participants in the intervention group would have greater improvements than those in the waitlist group in knowledge of breast cancer; selfefficacy in accessing information on cancer, managing the household, and communicating with health care providers; coping; and recovery care.

METHOD

We used a randomized control design, with approvals from the institutional review boards (IRBs) of the University of Hawai'i and Papa Ola Lōkahi. The latter is a community-based IRB that reviews research in Hawaiian communities for human protection and cultural and social impact issues (Braun, Tsark, Santos, Aitaoto, & Chong, 2006).

Participants

The four inclusion criteria for women were the following: (1) Native Hawaiian ancestry, (2) a diagnosis of breast cancer within the previous 10 years, (3) residence on Oʻahu or on a neighbor island with the ability to travel to Oʻahu during the study period, and (4) participation of a member of their family. *Family* was defined as being those people closest to the woman with

breast cancer, and it included both biological and nonbiologically related individuals. The participants from the neighbor islands (Big Island and Moloka'i) had to travel to O'ahu for cancer treatment as specialized oncology services were not available on these neighbor islands. Thirty-two women met the inclusion criteria and, of these, 29 (90.6 percent) women completed the study (15 intervention and 14 control). Two participants dropped out due to conflicts in scheduling, and another died during the study period. Noncompleters did not differ from completers on any of the demographic variables.

Conditions

Intervention. The intervention group received four, two-hour educational sessions over a fourmonth period, which provided materials and training in accessing information on cancer from the telephone and Internet, managing the household, and communicating with health care providers. We culturally tailored the intervention for Native Hawaiians in several ways (Mokuau & Braun, 2007). First, we featured Native Hawaiian characters and stories in recruitment and educational materials. Second, we packaged intervention materials, which included Hawaiian proverbs and scenes, in plant-fiber bags (lauhala), highlighting the woven bonds of the family. Third, we included cultural protocols, such as the use of prayer (pule), at the beginning of all sessions or a discussion of genealogy (mo 'okuauhau) in the delivery of the intervention. Fourth, we used the cultural discussion format referred to as "talk story" (kukakuka) in which there is an informal and reciprocal exchange of information. Fifth, we shared healthy and nutritious food (mea 'ai), with its emphasis on "feeding the spirit" within the family.

In session 1 (baseline), participants completed questionnaires and pretests and were provided with materials on breast cancer. In session 2, participants were taught how to access information and resources on the phone and Internet. In session 3, discussions emphasized how participants could ask family members to help with household tasks (for example, grocery shopping), transportation to medical appointments, and other activities that would promote recovery care. Session 4 focused on communicating with physicians and other providers about treatment choices, side effects, and other relevant issues. At the end of this session, questionnaires

were readministered and the feasibility evaluation was given. The majority of the sessions were held in the participants' homes.

Control. Participants in the control group had two sessions, most often held at their homes. At the first session, they completed questionnaires and pretests and received materials on breast cancer. At the second (and last) session at the end of four months, the questionnaires were readministered. Members of the control group were offered the intervention at the end of the study.

Measures

Demographics. A participant profile questionnaire solicited information, such as age, gender, marital status, educational level, occupation, and family history of cancer.

Knowledge. Developed from resources of the National Cancer Institute and the American Cancer Society, a 15-item true/false test was used to assess participants' knowledge on risk factors, cancer screening, cancer treatment, and follow-up care. We counted the number of correct items; the possible total scores ranged from 0 correct to 15 correct, with a higher score representing more knowledge.

Self-efficacy. A 20-item Likert scale on self-efficacy, developed for the study, assessed participants' confidence in accessing resources by the telephone and Internet, managing household roles and responsibilities, and communicating with health care providers. These items were scored on a 10-point scale (1 = not confident to 10 = very confident); possible total scores ranged from 20 to 200, with higher scores representing greater confidence. Based on pretest data (Mokuau et al., 2008), the scale's internal reliability was high ($\alpha = 0.91$). A moderate correlation (r = 0.64) between this scale and our measure of coping (Family Crisis Oriented Personal Evaluation Scale [F-COPES] total score, described below) supports its validity.

Coping. A 30-item standardized scale, the F-COPES, assessed family coping behaviors (McCubbin, Larsen, & Olson, 1982. It includes five subscales: (1) Social Support, (2) Reframing, (3) Spiritual Support, (4) Mobilizing Family, and (5) Passive Appraisal (reverse scored). Response options ranged from 5 = strongly agree to 1 = strongly disagree, indicating a family's response to a coping strategy. Possible total scores range from 30 to 150, with a high score representing a higher

number of coping strategies used. Based on previous research, the overall Cronbach's alpha reliability coefficient was .77; the reliability of the subscales ranged from .62 to .83; and the test-retest reliability for the final scale was .81.

Recovery Care. Developed from information from the National Cancer Institute and the Institute on Medicine, a seven-item questionnaire on recovery care was used to assess participants' vigilance on follow-up care after primary cancer treatment. Items assessed the degree to which the woman was in compliance with keeping scheduled follow-up appointments with physicians (for example, oncologists, primary care), performing breast self-exams, receiving clinical breast exams, and having mammograms.

Feasibility Evaluation. Intervention participants only were asked to complete a questionnaire about the overall study. There were 12 closed-ended questions about aspects of the intervention, which were scored from 5 = strongly agree to 1 = strongly disagree, as well as open-ended questions to assess the acceptability of the study protocol, study staff, educational materials, and the overall project.

Data Analysis

Data on knowledge, self-efficacy, and coping were analyzed separately for intervention survivors, control group survivors, intervention families, and control group families. To test the significance of changes over time, we used paired sample t tests on continuous variables and McNemar's chi-square on proportions. For the feasibility evaluation, we calculated the number of participants who agreed or strongly agreed with each statement, and we postcoded the responses to open-ended items.

RESULTS

Demographics

The 29 women–family dyads who completed the study represented both rural and urban areas on the islands of Oʻahu, Hawaiʻi (the Big Island), and Molokaʻi, including medically underserved areas with large proportions of Native Hawaiian residents living below the poverty level. Family members included husbands (10), daughters (11), sisters (5), a son (1), a boyfriend (1), and a friend (1). On average, participants were in their fifties, and family members were in their forties. More

than half were married. About two-thirds of each group had some post-high school education, and more than half were employed. Although not statistically significant, the participants in the intervention group reported a greater number of family members with cancer compared with the other three groups. One of the intervention participants reported that 20 family members had cancer; this high number likely skewed the sample. Participants in the control group reported a higher number of months post cancer diagnosis (22.1) when compared with the intervention group (14.2), but this difference was not statistically significant. All participants had health care insurance. There were no significant differences in demographic variables between the participants and family members in the intervention and control groups.

Knowledge, Self-efficacy, and Coping

Baseline and follow-up scores on knowledge, selfefficacy, and coping are shown in Table 1. Neither group increased in their knowledge of breast cancer. However, the participants and family members in the intervention group showed greater improvements than those in the wait-list control group in several other areas. For example, significant improvements in self-efficacy were seen for the women (p = .001) and their families (p = .006) in the intervention group but not for women and their families in the control group. Women in the intervention group showed significant improvement on their total F-COPES score (p = .05) and on the score for Social Support (.02); women in the control groups did not improve on any F-COPES measures. Family members in the intervention group showed significant improvement on their total F-COPES score (p = .001) and on scores for the subscales representing Social Support (p < .001), Spiritual Support (p = .002), and Mobilizing Family (p = .002).

Recovery Care

Changes in recovery care are shown in Table 2. This measure proved difficult to analyze, because each woman was on her own schedule for recovery care. Although we wanted to see whether the intervention helped women keep appointments with clinicians and for mammograms, some women were not scheduled for these appointments in the

Table 1: Baseline and Follow-up Outcome Measures						
	Par	ticipants	Family			
Measure	Control (n = 14) M	Intervention (n = 15) M	Control (n = 14) M	Intervention (n = 15) M		
Knowledge						
Baseline	12.79	12.33	12.93	12.00		
Follow-up	12.57	12.73	12.79	12.53		
Self-efficacy						
Baseline	167.43	158.60	166.50	154.67		
Follow-up	179.43	187.53	168.93	183.53		
F-COPES						
Social Support						
Baseline	31.64	33.53	31.79	30.60		
Follow-up	34.14	37.40	29.86	35.47		
Reframing						
Baseline	32.64	32.07	32.93	32.27		
Follow-up	33.93	34.00	32.57	33.33		
Spiritual Support						
Baseline	18.86	20.53	19.14	17.93		
Follow-up	19.50	21.53	18.0	20.13		
Mobilizing Family						
Baseline	17.00	16.20	15.64	15.53		
Follow-up	16.86	17.67	15.86	17.00		
Passive Appraisal						
Baseline	9.79	10.93	8.00	9.73		
Follow-up	9.64	12.13	7.93	9.87		
Total						
Baseline	114.00	114.67	114.64	110.33		
Follow-up	117.79	121.80	111.86	119.47		

Note: Significant changes are shown in boldface.

F-COPES = Family Crisis Oriented Personal Evaluation Scale.

Table 2: Number and Percentage of Women in Compliance with Recommended Recovery

Care Activities

	Control		Intervention	
Activity	Baseline n (%)	Follow-up n (%)	Baseline n (%)	Follow-up n (%)
Follow-up appointments	12/13 (92.3)	12/13 (92.3)	14/15 (93.3)	14/15 (93.3)
Breast self-exam				
Performance	8/13 (61.5)	8/13 (61.5)	8/15 (53.3)	13/15 (86.7)
Technique	8/13 (61.5)	8/13 (61.5)	6/15 (40.0)	12/15 (80.0)
Clinical breast exam, completed as recommended	12/13 (92.3)	12/13 (92.3)	9/9 (100.0)	9/9 (100.0)
Mammograms, completed as recommended	9/9 (100.0)	9/9 (100.0)	8/8 (100.0)	7/7 (100.0)

four months before or during the four-month study period. Thus, denominators varied depending on the item. For example, almost all women had at least one physician appointment scheduled during the four months preceding and during the study period, and all but one woman were expected to do breast self-exam (the exception was a woman in

the control group who had a mastectomy). However, mammograms were scheduled for only nine women in the control group and seven in the intervention group. When we compared percentages, the intervention appeared to increase the proportion of women who were performing breast self-exams with good technique but did not appear

to affect the proportion of women who were keeping appointments with clinicians and for clinical breast exams and mammograms.

Feasibility Evaluation

The findings from the feasibility evaluation, administered at the last session of the intervention, are shown in Table 3. Almost all participants and their families agreed that the sessions were the right length, that the educational materials were useful, and that they mastered the learning objectives of the intervention (for example, how to access cancer information and renegotiate household responsibilities). They appreciated the attention that was given to Hawaiian values and practices, the speaker phone and bulletin board, and the ability to meet at the location of their

Table 3: Feasibility Evaluation						
Response Item	Participants (n = 15) n (%)	Family (n = 15) n (%)				
The sessions were the right length of time.	15 (100.0)	14 (93.3)				
It was useful to have brochures, pamphlets, and other educational materials.	15 (100.0)	15 (100.0)				
It was useful to learn how to access cancer information by telephone and the Internet.	15 (100.0)	15 (100.0)				
It was useful to learn how families need to renegotiate their household <i>kuleana</i> (responsibility).	15 (100.0)	14 (93.3)				
It was helpful to learn about communicating with my health care provider.	15 (100.0)	14 (93.3)				
I appreciated attention to Hawaiian values in sessions.	15 (100.0)	15 (100.0)				
I appreciated the use of Hawaiian practices.	14 (93.3)	13 (86.7)				
Telephone, bulletin boards, and other materials were useful.	14 (100.0) ^a	15 (100.0)				
It was helpful for the participant to choose the meeting place.	15 (100.0)	15 (100.0)				
I felt comfortable with members of the research team.	15 (100.0)	15 (100.0)				
Questions were clear and easy to understand.	14 (93.3)	15 (100.0)				
I would recommend this project to other Native Hawaiians with cancer.	14 (100.0) ^a	15 (100.0)				

Note: Response options ranged from 5 = strongly agree to 1 = strongly disagree. Shown are number of participants who agreed or strongly agreed with each statement. "Only 14 answered. choice. In regard to the research, they reported feeling comfortable with members of the research team and the measures, and they would recommend the project to other Native Hawaiians.

Several participants also provided qualitative responses that expressed their value of the project. One participant said, "The thing I like best about the project is ... it gave me a voice." A family member wrote about how happy and proud she was to have the knowledge and skills to help her mother: "I have learned so many things on how to correctly help my mom and what to expect." The project also appeared to have a ripple effect. For example, 11 of our participants have daughters as their family members. These daughters improved in their health care, especially after learning that family history is a risk factor for breast cancer. Several told us that they scheduled appointments for mammograms. Also, several participants asked for cancer information materials for their friends. One participant wrote that the sessions "helped me to pass on information to people I know with same condition that do not have information. We can help others to deal with this terrible disease."

DISCUSSION

In striving for a healthy nation for 2020, the U.S. Department of Health and Human Services (2010) established the goal to "achieve health equity, eliminate disparities, and improve the health of all groups." Overall, health for many Americans has improved in recent years; but for Native Hawaiians and other racial and ethnic minority populations, there continues to be compelling evidence of persistent and sometimes increasing disparities (Centers for Disease Control and Prevention, 2009). In particular, Native Hawaiian women have high breast cancer incidence and mortality rates and are diagnosed at significantly younger ages and more advanced stages than the other ethnic groups in Hawai'i (Hawai'i Cancer Facts and Figures, 2010). The growing literature indicates that family support can reinforce women's efforts to stay healthy after a breast cancer diagnosis (Baider et al., 2000; Veach et al., 2002). For a population such as Native Hawaiians, whose cultural values are organized around a collective orientation and a focus on family, building family capacity may reduce the burden of breast cancer.

Specifically, members of our intervention group showed significant improvement in self-efficacy in accessing information on cancer, managing the household, and communicating with health care providers and in coping skills; members of the control group did not. Improved self-efficacy in intervention group members may be attributed to the face-to-face training, personalized coaching, and training in the home environment where the milieu is familiar to participants. The participants who resided on the Big Island and Moloka'i and traveled to O'ahu for oncology services that were not available on their islands did not benefit from our home-based services, but they did express an appreciation for our flexibility in meeting with them when they had scheduled appointments with their oncology providers. Improvements in coping skills relevant to social support, spiritual support, and family mobilization for the intervention group may be attributed to training sessions that are anchored in the family unit and that reflect Native Hawaiian cultural values and practices. When confronting a life-threatening disease such as cancer, the relationships of person-family-spiritual realm are magnified in importance in Native Hawaiian culture and serve as a basis for coping (Mokuau, 2011). For many Native Hawaiians, there may be a reliance on familial support to assist them in making connections with external resources, such as those sponsored by hospitals and other health care organizations (Gotay & Lau, 2003). We believe that strengthening these connections and relations had a direct impact on improved coping skills among members of the intervention group.

Although participants were positive about the intervention, recruitment was a challenge of this project. To recruit participants, we established relationships with numerous organizations and key leaders in the health care community; broadly distributed our brochure; and presented our project through newsprint, radio, and television media. However, only 37 (74 percent) participantfamily dyads, out of a target of 50, volunteered for the study. Although we did not achieve our target, our rate is higher than that of other authors who have also reported difficulties in enrolling breast cancer participants. Ferrante, Chen, and Kim (2007) had a low enrollment rate of African Americans in their study (36 percent) and cited distrust as the most common reason for refusal. Moy et al. (2010) recruited study participants through intensive community outreach, including repetitive, face-to-face approaches by the community leader, but achieved a limited response rate (29 percent). For future studies, we believe that it is important to nurture community and social networks in health care to recruiting Native Hawaiian participants. Anchoring recruitment activities with an employee in a health program or hospital may improve the dedicated efforts to increase enrollment and may also increase the likelihood that women continue to access services and complete recovery care.

Once in the study, however, more than 90 percent of participants and family members in the intervention group gave the study "good marks" in regard to retention, study protocol, and measures. The high retention of intervention participants is attributed to the personalized approach, the attention to cultural values, and the usefulness of knowledge and skills from the intervention. In addition, these women stayed in the study because they were invested in their recovery and valued the approach in which their families were also included as active participants. Approaches that include families in psychosocial assistance may enhance study participation (Baider et al., 2000). Other research shows that there is increasing use of the Internet to support breast cancer patients in retrieving information (Satterland, McCaul, & Sandgren, 2003) and for increasing cancer screening compliance among Native Hawaiian women (Tran et al., 2010).

Findings confirm what other researchers have suggested-an intervention can and should attend to a culture's surface and deep structures to ensure that it is attractive and salient to people from that culture (Kreuter et al., 2002; Resnicow et al., 1999). As noted, our intervention built on the values of extended family ('ohana), spirituality (ho 'omana), and responsibility (kuleana). Also, materials featured Native Hawaiian faces and proverbs, and the intervention incorporated cultural protocol, such as prayer (pule) and exchange of genealogy (mo 'okuauhau). Social workers are well positioned to help organizations develop and implement culturally tailored interventions given their skills in assessment and culturally competent practice. This study provides an example that can be followed by social workers who want to tailor interventions to other minority groups and test the effectiveness of these interventions.

The findings also demonstrate that the intervention helped empower individuals to improve their self-efficacy. Self-efficacy theory posits that self-control is a key factor in health promotion and that individuals and their families can "take control" of their health if they are helped to gain knowledge, skills, and confidence in their abilities to manage health challenges (Bandura, 1997). Interventions on self-efficacy are in line with national initiatives on health care reform that call for the active participation of people in securing optimal health care at lower costs (Patient Protection and Affordable Care Act) (P.L. 111-148).

More research is needed to determine whether the incorporation of components of our research into other cancer programs will result in similarly positive increases in self-efficacy and coping skills among Native Hawaiian cancer patients. A strength of our intervention was the ability to spend considerable time with each family during the four intervention visits. However, such commitments of time may not be possible, as anecdotal information from the cancer patient navigation programs in Hawai'i suggest that a navigator's case load may limit the amount of time he or she can spend with each patient and family. Another key area to research is the link between increased self-efficacy and health outcomes. Although we found evidence that women in the intervention group made more improvements in breast self-exam behaviors than did women in the control group, we did not track patients over the long term to gauge cancer survivorship and recurrence. More longitudinal studies are needed to study these linkages.

Finally, interventions like ours will have no effect on future cancer patients unless they are deemed to be universally needed, integrated into the standard of care, and appropriately reimbursed. To date, many survivorship programs are funded through grants. There is need to move culturally tailored, evidence-based interventions from grant support to full integration in health care systems. Such culturally tailored interventions need to be "hard-wired" into health care systems to truly hold to the promise of reducing the overall burden from cancer for Native Hawaiians and other high-risk populations.

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