Family Support for Native Hawaiian Women with Breast Cancer

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Abstract—Background. A cancer diagnosis affects not only the individual but the entire family. Despite the growing body of literature on family support as a resource in cancer care, there is very little research on how cancer affects families in non-Western cultures. A minority population that experiences a disproportionate burden from cancer is Native Hawaiian women. Methods. In this study, 8 Native Hawaiian women with breast cancer and 17 family members of other Native Hawaiian women with breast cancer participated in focus groups examining family support. Specifically, types of support provided by the family (eg, informational, emotional, and tangible), changing dynamics of family roles, and recommendations for health care providers, with attention paid to the influence of culture on family support, were topics that were examined. Results. Similarly to other populations, Native Hawaiians viewed the family as the most important source of emotional and tangible support for women with cancer, and identified a need for increased informational support for both patients and families in the face of cancer. However, their reference to specific cultural values and practices within the 'ohana (family) [eg, haku (family liaison) and ho'omana (spirituality)] reflects a uniqueness that has implications for clinical work with this population. Conclusions. Consideration of cultural values and practices may enhance health care services for this population. J Cancer Educ. 2007; 22:191-196.

About 1.2 million Americans were diagnosed with cancer in 2002, a diagnosis that affects not only the individual but the entire family. The family is a principal resource that provides the social support that can reduce the stressors associated with the disease and facilitate adjustment. Components of social support include informational (provision of knowledge; helping to access information), emotional (perceived demonstration of caring), and tangible (specific assistance such as transportation to a medical appointment and childcare) support.

The impact of a woman’s cancer has unique ramifications because of the central role that women assume in family life. Women tend to be responsible for the management of the home, the nurturing of children, and the care of nuclear and extended family members. When confronted with cancer, however, a woman may be restricted in her capabilities to carry out family functions, and family support becomes important in stabilizing the family and managing the stressors associated with a life-threatening disease.

Despite the growing body of literature on family support as a resource, there is very little research on how cancer affects families in non-Western cultures. Culture is an important determinant of family support in cancer care and can significantly influence how an individual and her family understand and respond to the cancer experience. Understanding the “powerful interaction of cancer, family and culture” will facilitate work with diverse, minority populations.

A minority population that experiences a disproportionate burden from cancer is Native Hawaiians. Native Hawaiians are indigenous to the islands of Hawai‘i and comprise 20% of the approximately 1.2 million residents; other major ethnic groups include Whites (about 25%), Japanese (about 23%), Filipinos (about 17%), and Chinese (about 5%). Hawai‘i is reputed to have the best health status in the nation, yet Native Hawaiians have the second highest age-adjusted cancer death rates. In Hawai‘i, Native Hawaiian women have the highest mortality rates for multiple types of cancer including breast, lung, liver, pancreas, cervix uteri, corpus uteri, stomach, and rectum. Analyses of Hawaii Tumor Registry data show that Native Hawaiian women are more likely than women in other ethnic groups to be diagnosed at younger ages and later stages of disease.

Other reasons for continued ethnic differences in breast cancer survival in Hawai‘i may include culture, socioeconomic status, access to insurance, comorbid conditions, screening appropriateness, treatment compliance, and tumor aggressiveness. Looking more specifically at culture, research in Hawai‘i suggests that Native Hawaiians who subscribe to traditional cultural practices may not utilize health care services that are “Western” in orientation.
and inconsistent with their values and customs. In contrast, those interventions that incorporate cultural values have been found to be successful in increasing breast health practices such as breast self-examinations among Native Hawaiian women. Cultural values that are significant are associated with the ‘ohana (family).

The purpose of this study was to examine family support for Native Hawaiian women with breast cancer, looking specifically at the role of culture. The importance of the family in the support of Native Hawaiian women with breast cancer is an area of requisite exploration that can contribute to improving our understanding of and services to an overburdened population.

**METHODS**

Formative research, with its attention on defining the target population to better develop interventions/programs that will assist them, is appropriate for this study. Focus groups are commonly used in formative research to explore a target population’s values, meanings, and perceptions of a phenomenon. This methodology allowed investigators to hear the stories of how cancer impacted the family and how Native Hawaiian women with breast cancer were (or were not) supported by their families. Additionally, focus groups fit with Native Hawaiian culture, which includes an oral-aural tradition, a preference for collective learning, and an emphasis on face-to-face meetings that allow people to gauge trustworthiness.

The participants for this study were 8 Native Hawaiian women who had breast cancer and 17 family members of other Native Hawaiian women who had breast cancer. In an effort to increase the number of stories we heard, the 17 individuals in the family-member sample were not related to the 8 in the cancer-survivor sample. Recruitment occurred through referrals from the staff of ‘Imi Hale, a Native Hawaiian project funded by the National Cancer Institute, and from Native Hawaiian leaders in the community. In addition, flyers on the study were circulated in Native Hawaiian organizations. In all, 40 individuals were approached and 25 (63%) participated: 17 of 25 (68%) family members, and 8 of 15 (53%) women who had breast cancer. Those who refused (8 family members and 7 breast cancer patients) cited lack of time and not wanting to revisit the cancer experience.

Discussion was organized around 3 topic areas: (a) the family support system and the helpful (and unhelpful) things they did, (b) the changing dynamics of family roles and responsibilities, and (c) recommendations for strengthening family support. Guidelines were developed that were suitable for the 2 different groups—women with breast cancer and family members. The questioning was open ended and semistructured, providing direction for discussion but permitting flexibility to explore unique contributions of culture. This protocol was developed in consultation with 5 Native Hawaiian key informants who are specialists in health and pretested with 2 Native Hawaiian women with breast cancer and 3 family members. Participants completed a short demographic survey that gathered information on age, gender, marital status, employment status, education, and family history of cancer.

A Native Hawaiian social worker, assisted by 2 graduate social work students, facilitated 6 focus groups over a 4-month period. Informed consent was obtained for every participant. Each group lasted approximately 2 hours. As individuals responded to focus group questions, key concepts were written on posted newsprint to assure that members’ impressions were captured accurately. All sessions were tape-recorded.

Cultural protocol was observed in all focus groups. For example, sessions would begin with a pule (prayer) most frequently offered by a kapuna (elder) in the family but on occasion rendered by the facilitator. These prayers emphasized the importance of spiritual guidance of the discussion. In another example, participants were given a makana (gift) of $20 for their contribution and provided with a light meal, emphasizing reciprocity as a cultural norm.

Conversations were transcribed, with each remark attributed to its speaker. Researchers independently read the transcripts to identify the themes and the role of culture. Once a codebook was developed, investigators reread the transcripts, noting which participants supported each theme and highlighting illustrative passages. In general, there was high agreement among investigators on themes and which individuals spoke to each. When investigators disagreed on how to code a particular statement, the statement was discussed until consensus was reached on how to code it.

**RESULTS**

The mean age of the 8 Native Hawaiian women with breast cancer was 68 (range, 43-84). Of these, 2 were married, 4 were widowed, and 2 were divorced or separated. Half were retired. In comparison, the mean age of the 17 family members was 46 (range, 26-69); 3 were male, and 10 were married, 4 were never married, and 3 were widowed or divorced. All 25 participants had completed high school, and more than 60% of each group had attended at least some college. Approximately 90% of participants (5 of the 8 women with breast cancer and all 17 family members) reported a family history of cancer. In fact, 16 participants (64%) (4 women with breast cancer and 12 family members) reported 2 or more family members with cancer.

The data are presented in 4 areas: (1) sources of support, (2) types of support, (3) changing dynamics of family roles, and (4) recommendations for health care providers (Table 1).

**Sources of Support**

Every participant emphasized the importance of family support, with 1 survivor stating “ohana (family) involvement was the key to helping me though the experience.” Within the family, 1 person was identified as the haku (primary