Hispanic Women with Breast Cancer:
Addressing Disparity in Community Based Support Groups in Portland-Metro, Oregon

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Abstract

As medical treatments have improved, breast cancer survivors (BCS) are living longer than ever, and many experience severe psychosocial challenges impacting quality of life (QOL) long after treatment ends. Hispanic breast cancer survivors (HBCS) may suffer these challenges more often and more severely than white women. Issues unique to their culture create added barriers to accessing supportive care. The Institute of Medicine’s (IOM’s) 2008 report *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* called for patients, providers and community agencies to work together to meet these psychosocial needs through evidence-based methods including support groups.

Support groups for women with breast cancer are plentiful in the Portland-Metro area however Hispanic women derive less benefit from support groups for the general population of BCS, than women of other cultures do. Nationally there has been recent growth in culturally-specific support groups. Although the evidence of the value they offer to HBCS is clear, there are none in this area. Two non-profit agencies in the Portland area, Breast Friends and Familias en Acción, offer breast cancer support groups. The support group offered by Breast Friends is open to all female BCS. Familias en Acción runs a support group for all Hispanic cancer survivors, both men and women together. Neither group is specific to the needs of HBCS. Both agencies report inadequate resources to fund a Hispanic breast cancer support group. Surprisingly these two well established and successful agencies know very little about the other. Future collaboration between these two agencies presents opportunities to provide evidence-based, culturally and linguistically appropriate support groups for this population in need.
Meeting the Psychosocial Needs of Hispanic Breast Cancer Survivors

Introduction

Breast cancer is the second most common cancer among all women in the United States, with the highest incidence in non-Hispanic White women. But for Hispanic women breast cancer is the leading cancer diagnosis, the leading cause of cancer death and one in every 11 will develop invasive breast cancer in her lifetime. Hispanic women are more often diagnosed at advanced stage, and require more aggressive treatments, associated with more severe side effects. For all these reasons Hispanic women frequently have greater psychosocial needs than other groups (American Cancer Society, 2012).

This analysis focuses on the psychosocial needs of HBCS in the Portland-Metro area. They predominately live a distance from the center of Portland, in population clusters near the outer boundaries of the metro area and Multnomah County, and close to farming and labor employment (Multnomah County, 2012).

Psychosocial Needs of Breast Cancer Survivors

The Institute of Medicine’s (IOM’s) 2008 report Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs called attention to the importance of addressing psychosocial needs of cancer survivors, who due to improved diagnosis and treatment, are living longer than ever. Quality cancer care includes providing information and tools to manage psychosocial problems caused by the disease or its treatment. Patients, the health care system, and the community must work together to identify unmet psychosocial needs, develop culturally-appropriate services, and connect patients with supportive care aimed at meeting those needs (IOM, 2008).
BCS experience a range of short and long-term challenges due to their diagnosis and treatment, which for some can be quite severe and often continue to impact their QOL long after treatment ends. Breast cancer and its treatment impact QOL in physical, psychological, social and spiritual domains (Ferrell & Grant, 2006). In the year following diagnosis a wide range of problems impact QOL, including treatment decisions, side effects, overwhelming fear of recurrence and death, sleep disturbances, depression and anxiety, and challenges with managing everyday life (Ashing-Giwa1, Rosales, Lai, & Weitzel, 2012).

When treatment ends, heightened concerns of recurrence and ambivalence are common, due to fear that nothing is being done to prevent cancer from recurring (Corvin, Coreil, Nupp, & Dyer, 2013). Frequently partners and friends may withdraw support when treatment ends, perceiving women have less need, but this leaves many women feeling isolated and increasingly vulnerable (Knopf, 2007).

**Unique Psychosocial Needs of HBCS**

HBCS are reported to suffer these same psychosocial problems, but to a greater degree than the general population of BCS. Hispanic people struggle with culturally rooted economic and psychosocial issues that worsen barriers to accessing supportive care (Corvin et al., 2013). Higher poverty rates, lack of insurance, language barriers, and lower educational and health literacy levels, are common in HBCS (Curry-Stevens, 2012). The State of Oregon (2011) reports Hispanic women earn 40.5% less than White women. Poverty results in a lack of child care and transportation (ACS, 2012b), and is shown to magnify depression in HBCS (Christie, Meyerowitz, and Maly, 2009).
When treatment ends, HBCS report greater negative feelings, appearance concerns, worry about the impact of their illness on their family, fear of recurrence, and social avoidance than White women (Carver, Smith, Petronis, and Antoni, 2006). Normally Hispanic women rely on social interaction for opportunities for emotional support and information sharing, and social interaction has been shown to strengthen coping skills, and improves survival. Thus HBCS who do not have access to social support or who avoid social interaction because of cancer related issues may experience decreased survival (Chou, Stewart, Wild and Bloom, 2012).

**Support Groups**

Cancer support groups are the most common format of psychosocial support for male and female cancer survivors, regardless of type of cancer. BCS regardless of race or ethnicity report they receive optimum psychosocial support in breast cancer specific groups, where they can connect with other women who have had similar challenges dealing with their disease (Corvin et al., 2013).

The evidence is overwhelming that all BCS benefit from attending a breast cancer support group, but Hispanic women derive significantly less benefit from attending non-culturally specific groups. Evidence is considerable that Hispanics are not comfortable disclosing personal information and feelings to non-Hispanics (Lopez-Class, Perret-Gentil, Kreling, Caicedo, Mandelblatt, & Graves, 2011).

Ethnic minorities have traditionally been less likely to participate in support groups for the general population of survivors. As a result an increasing number of ethnic-specific cancer support groups have been formed as a way to encourage minority
participation in the best option available to help patients cope with a diagnosis of cancer (Corvin et al., 2013).

**Hispanic Breast Cancer Support Groups**

HBCS prefer attending culturally specific support groups, which typically have a strong spiritual component with a lot of social interaction, sharing of food and music. Social norms in these groups include a higher acceptance of sharing strong emotional expression. This includes crying in group, and the entire group will commonly cry together (Corvin et al., 2013).

Best practice for the facilitator of any HBCS support group includes a deep understanding of Hispanic culture. A strong facilitator who is knowledgeable, outgoing, creative, upbeat and empathetic is essential for success (Corvin et al., 2013). In order to be effective, support group leaders should engage HBCS by asking about their life, family friends and work, so that they will share life stories, and encourage them to ask more questions. “Respect is highly valued, so support group leaders must both take seriously the respect that is given them, and be respectful of participants, being careful to explain without being condescending (Borrayo, 2009).

Mixed gender groups have been less successful for HBCS, probably due to elevated values in Hispanic culture for modesty and privacy. The breast is considered a very private part of the Latina’s body, and treatment for breast cancer often causes hormonally-mediated treatment side effects, which are particularly sensitive for Hispanic women to discuss openly in a mixed gender group (Borrayo et al., 2009).

Finally location is an important issue to be considered when offering support groups for HBCS. Logistically accessible meeting locations are essential since low
socioeconomic status makes it difficult to attend meetings held far from home (Ashing et al., 2012).

**Community Agencies**

**Breast Friends**

Portland-Metro is home to Breast Friends, a non-profit agency founded in 2010 by two BCS, for the purpose of improving the QOL of BCS, spouses, partners and families, both during treatment and into survivorship. They are the largest and best well known community agency offering supportive resources, including support groups, to help BCS and their families cope with BC (Breast Friends, 2014).

Breast Friends offers monthly support groups for BCS in six geographically distant areas of Portland-Metro, three that are close to areas of Hispanic population density, with one in East County. These groups have been ongoing for several years and are very well attended. Group facilitators are all BCS with focused training and expertise in moderating meeting, and thus far every facilitator has been white, and most participants have also been white. They do not offer a Hispanic specific group (Breast Friends, 2014).

Breast Friends co-founder Sharon Henifin has been a group facilitator for more than ten years. Sharon admits they have little to offer women who don’t speak English, or who have culturally specific support needs. She reports very few HBCS have attended any of their groups on a consistent basis. The few HBCS, who have participated, have spoken English very well. African American and Asian women also rarely attend (S. Henifin, personal communication, February 22, 2014).
Co-founder Becky Olson explained they have never considered adding culturally specific groups, saying she “hadn’t really thought of that” (personal communication, February 21, 2014). She explained that they have limited finances, they already have a full plate, and they lack a bilingual group facilitator. Other reasons given include: 1) They hadn’t recognized there was an unmet need, 2) All of their groups have sustained regular attendance, and 3) They haven’t been approached by other agencies, BCS, or health care providers to start a Hispanic only group (B. Olson, personal communication, February 22, 2014). Sharon recognized the name of Familias en Acción, but has never met or spoken with anyone from FA. Sharon says “we are just are not well equipped to support them, and I really don’t know who is, so there must be a great need” (Personal communication, February 22, 2014).

**Familias en Acción**

Familias en Acción is an agency focused on promoting holistic family well-being for Hispanics in this community, with two programs for cancer survivors including the Hispanic Patient Navigator Program and a support group. Theirs is the only Hispanic cancer support group in the Portland-Metro area, but it is not specific to BC. Meetings are held at Agustana Lutheran Church in Inner-Northeast Portland. The location is central to the Hispanic population in the area, but not convenient to any of them, including those living in East/Mid-County. The Familias en Acción support group is “a refuge and safe haven” for Hispanic survivors who have “faced cancer, barriers to care or a lack thereof, deportation, unemployment, discrimination and have still found refuge in their spirituality to survive and live at their best” (Familias en Acción, 2014).
Betsy Velazquez has been running their group for over three years. She reports they have regular participation of between 15-30 cancer survivors. Several BCS have attended this mixed-gender group, continuing to take part for a significant duration, but not as many as would be expected given the incidence of breast cancer in this population. Feedback from participants is that attending has helped them to feel more optimistic (B. Velazquez, personal communication, March 5, 2014).

The location selected is central to all the outlying areas which have large populations of Hispanics, nevertheless poverty and lack of transportation create barriers for participation. Unfortunately Familias en Acción lacks the resources necessary to provide separate groups in each community. Too few BCS attend to justify a group just for breast cancer at Augustana (B. Velasquez, personal communication, March 5, 2014).

In this community HBCS have the option of attending a breast cancer support group for women of all ethnicities through Breast Friends, or the Hispanic group for all cancer survivors including men that is offered by Familias en Acción. Neither option fits the unique needs of this population. Culturally and linguistically appropriate support groups are needed for HBCS, as is increasing awareness of these services among community agencies, primary care providers, oncologists, patients and family members (Nápoles-Springer, Ortíz, O’Brien, Díaz-Méndez, & Pérez-Stable, 2007)

**Proposed Solution**

Ideally Breast Friends and Familias en Acción should work together because they share a common mission of improving the health and well-being of HBCS in this community. At this time no relationship exists between the two agencies. However collaboration can be achieved over time through an outgrowth of networking,
communication and coordination efforts. Initial steps involve bringing key representatives of these two agencies together so they can be introduced and begin exploring areas where organizational goals overlap. Through the process of working together these two agencies have the potential to increase the impact of their partners by sharing information, knowledge, and other resources (Minkler & Wallerstein, 2012).

Collaboration by Breast Friends and Familias en Acción would require a change of strategy, from thinking about programs and group services, to searching for more complex integrated strategies (Minkler & Wallerstein, 2012). Breast Friends is a member of the community of BCS and Familias en Acción is a member of the cultural community of Hispanics. Together these two agencies could offer HBCS support groups within the communities they live in, so that meeting locations are convenient to home.
MEETING THE PSYCHOSOCIAL NEEDS OF HISPANIC BREAST CANCER SURVIVORS

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