Addressing Disparities: The Alliance Breast Cancer Community-Based Program for Hispanic Women

Ana C. Sanchez-Birkhead, PhD, WHNP-BC, APRN, Sara Carbajal-Salisbury, BS, Jorge Arce Larreta, MBA, Hilary Hendricks, MBA, and Susan L. Beck, PhD, APRN, FAAN

Background: The Alliance Breast Cancer (ABC) program is a community-based initiative developed and implemented to address the needs of Hispanic women faced with a cancer diagnosis or cancer survivorship issues.

Objectives: This article evaluates the effectiveness of a community effort to address breast cancer-related disparities among Hispanic women.

Methods: Nurse scientists collaborated with program staff to conduct a systematic five-year program evaluation. Data sources included monthly and annual reports, participant tracking databases, and an annual satisfaction survey.

Findings: Hispanic breast cancer survivors who participated in the program expressed feeling very satisfied with the services and believe that it addresses the specific barriers faced by this population. The ABC program serves as a best practice example to other communities forging partnerships to address health disparities and community needs in a culturally tailored manner.

Culturally tailored interventions are needed at the community level to address cancer-related disparities among the growing number of underserved and diverse populations. This program description and evaluation focuses on a community effort to address breast cancer-related disparities among Hispanic women. The Alliance Breast Cancer (ABC) program is a community-based program that addresses local, cultural, and family-based needs, spanning the continuum of cancer care. With its three integrated components—educational outreach and screening assistance; a support group for women in treatment, survivors, and their loved ones; and in-home visits by trained fellow survivors—the program removes barriers to breast cancer screening and provides supportive care for Hispanic women and their families after a cancer diagnosis.

Clear disparities in the health and survival experiences of Hispanic women with breast cancer persist. Cancer has replaced heart disease as the leading cause of death among Hispanics in the United States (American Cancer Society, 2015b), and breast cancer is the most commonly diagnosed cancer and the leading cause of cancer death among Hispanic women (Buki et al., 2008). Although rates of breast cancer are lower for Hispanic women than for Caucasian or African American women, Hispanic women are more likely to have significant sequelae and die from breast cancer, as well as become seriously ill, compared to their Caucasian counterparts (American Cancer Society, 2015a). These disparities are due, in part, to lack of access to adequate care, language barriers, lack of insurance, later stages of presentation, and a lack of understanding about treatment options (Juarez, Hurria, Uman, & Ferrel, 2013; Martinez-Ramos, Biggs, & Lozano, 2013).

Health disparities for Hispanic women span the continuum of care. Lower rates of early screening for Hispanic women and time delays to a definitive diagnosis can result in later detection of breast cancer and a decreased chance for survival (Ramirez et al., 2013). Disparities also affect the
experience of survivors. In a systematic review of 22 studies, Yanez, Thompson, and Stanton (2011) determined that Hispanic breast cancer survivors were more likely to report poorer physical, mental, and social quality of life than their Caucasian counterparts. A growing body of research on supportive care needs for Hispanic women with breast cancer suggests that these women have greater social, psychological, and physical needs (Livaudais et al., 2010; Yoon et al., 2008).

A few community-based initiatives have been developed to address the unique needs of Hispanic women with breast cancer. Reports indicate that these cancer support programs have positive and beneficial effects for breast cancer survivors and their families (Nápoles-Springer, Ortiz, O’Brien, & Díaz-Méndez, 2009). Community-based efforts provide a unique opportunity to offer culturally tailored support across the continuum of care.

Two approaches used in many programs involve promotoras and navigators. In promotora models of community-based care, trained community members provide outreach and general health education (Pratt-Chapman, Simon, Patterson, Risendal, & Patierno, 2011). Navigators are focused on reducing barriers to care and promoting certain behaviors, such as mammography screening for a specific population. Growing evidence supports the use of patient navigators to improve screening rates and patient adherence (Ramirez et al., 2013; Robie, Alexandru, & Bota, 2011; Sheppard et al., 2008).

More evaluation research is needed regarding community-level programs to address cancer-related disparities among Hispanic populations (Allen, Shelton, Harden, & Goldman, 2008). The following needs assessment, program description, and program evaluation seek to address this knowledge gap.

Local Needs Assessment

The Hispanic community in Utah has grown exponentially since the early 2000s. Hispanics now comprise 13% of the state population and 19% in Salt Lake County, the most populous area (U.S. Census Bureau, 2014). The breast cancer occurrence rate in Utah for 2010 was 101.68 per 100,000, which is lower than the national average reported at 122.54 per 100,000. There were 5,815 new cases of breast cancer in Utah from 2004–2008, and about 300 of these were in Hispanic women (Susan G. Komen Foundation, 2011). Utah has one of the lowest mammography screening rates in the country, with less than 68% of women aged 40 and older in the state reporting having had a mammogram within the past two years—significantly below the national average of 76%. The largest gaps existed in women who have no health insurance, with only 38% reporting having had a mammogram, compared to 71% of women with insurance (Susan G. Komen Foundation, 2011). About 40% of Hispanics in Utah lack health insurance (Pew Research Center, 2011). In addition to the challenge of inadequate insurance, Hispanic women in Utah, as in many locations, experience other barriers that delay their access to cancer screening and to treatment after being diagnosed. These barriers include lack of a medical provider, lack of transportation, language difficulties, limited understanding regarding their diagnosis and treatment options, and lack of familiarity with the healthcare system in the United States (Galván, Buki, & García, 2009; Harrison, Young, Price, Botow, & Solomon, 2009). For undocumented residents, fear of being detained or deported can also keep women from seeking screening and treatment. Through its culturally tailored programs, the ABC program was designed to address these disparities.

Program Description

In an effort to address the growing need to educate, screen, and provide cancer supportive services for Hispanic families in Utah, Alliance Community Services (ACS) formed the ABC services program. ACS is a nonprofit organization founded in 2002. The mission of ACS is to improve the well-being of Hispanics and underserved individuals by making social and preventive health services accessible to them. The bicultural staff includes professionals from diverse multietnic backgrounds with vast experience in human resources, health and social services, education, communication, planning, and program evaluation. This blend of skills, education, experience, and cultural backgrounds contributes to a unique outreach effort that provides services in an efficient and cultural manner.

Nurses have partnered to support the ABC program staff in several ways. Oncology nurse faculty from the University of Utah serve on the advisory board for the program and provide input into programming and evaluation. They also offer direct program support by providing educational presentations to the breast cancer survivors on topics such as pain, fatigue, stress, and sexuality. An advanced practice nurse from the Utah Cancer Control Program (UCCP) at the state health department has consistently supported the group through educational presentations and direct patient support, and has facilitated the partnership between the ABC program and the UCCP to provide direct care (breast screening and follow-up).

The ABC program is unique in several ways. First, the program addresses needs across the continuum of care, from screening to cancer detection to supportive care. Second, the program reaches women from the many subcultures of the Hispanic population who live in Utah, including women whose origin is from Mexico as well as most Central and South American countries. The program is built on partnerships with community stakeholders, including the UCCP, the Salt Lake County Health Department, Intermountain Medical Center (IMC), the College of Nursing at the University of Utah, local clinics, local Spanish-language media, and local schools and churches. The ABC program offers guidance, education, and emotional support to women and their families, and medical services are provided at a free or reduced cost through community partners. Legal status is not addressed, so women feel safe in seeking needed resources offered by ABC.

The ABC program consists of three integrated components: outreach and screening, an educational support group, and a peer home visiting program.

Outreach and screening: The first component is an outreach and educational initiative, which promotes the importance of routine clinical breast examinations, annual mammograms,
and monthly self-breast examinations to low-income Hispanic women residing in the population-dense counties of Utah. The program has been supported through funding from the Avon Foundation Breast Care Fund, Utah Cancer Action Network, Susan G. Komen Foundation, American Cancer Society, and Livestrong Foundation. Two trained Hispanic patient navigators bring sensitivity to the culture and community through the breast cancer screening program. They arrange screening, transportation, and interpretation services. Free or low-cost screening and travel services are arranged through the UCCP or IMC, or via vouchers from local institutions. Through collaborative agreements, the patient navigators follow up with providers, verify completion, and identify women diagnosed with cancer. Navigators maintain a complete database that allows them to track and call women to encourage annual re-screening. The patient navigators then support any woman diagnosed with breast cancer, many of whom are uninsured, in seeking treatment and accessing care, including the other ABC programs, Triunfadoras and Entre Amigas. They also conduct one-on-one and group educational sessions about breast and cervical cancer screening in a variety of community settings, including health fairs and special community events.

**Triunfadoras support group:** The second component, Triunfadoras, is a monthly support group of Latina breast cancer survivors that provides education, support, access to community resources, and physical activity classes (yoga and Zumba). The program has been funded by a grant from the Susan G. Komen Foundation and grassroots fundraising efforts. This program helps Hispanic women and their families who are affected by breast cancer learn about the illness, gain coping and survivorship skills, and share experiences with other women of the same ethnicity. Each educational program and support group meeting is offered in Spanish and presented in a culturally sensitive manner. Women often bring their husband, partner, or a loved one, and although the program is not directed at them, these guests sometimes contribute significantly to the discussion.

The meetings are held in the early evening for two hours. The first hour is an educational program provided by expert nursing, medical, and other health professionals from the community. Topics are suggested by the survivors and the advisory committee. Included topics are related to cancer treatment (e.g., chemotherapy, breast reconstruction), symptom management, strategies to cope with stress and changes in sexuality, information on healthy behaviors such as exercise and nutrition, and the effect of cancer on families. Following a light meal, a facilitator leads an hour of sharing and support. Group facilitators provide information and referrals to numerous community resources, including programs such as Look Good, Feel Better (www.cancer.org/treatment/supportprogramsservices/look-good-feel-better) and Image Reborn (www.imagerebornfoundation.org/about.php). Social networking activities bring the flavor of Hispanic heritage, including special events for Mother’s Day, a summer picnic, and a Christmas potluck. Outreach methods include a monthly newsletter, an email Listserv, and a network of survivors who call participants and encourage attendance at the monthly meeting and events.

**Entre Amigas home visits:** The third component, Entre Amigas (Spanish for “Among Friends”), is a culturally designed program modeled after the American Cancer Society’s Reach to Recovery program. Breast cancer survivors are trained as promotoras to provide peer support at home to survivors who are physically unable or choose not to participate in the larger support group. They offer one-on-one education, emotional support, and information on how to access community resources to enhance medical compliance with

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<tr>
<th>TABLE 1. Participants in Alliance Breast Cancer Program Activities From 2009–2013</th>
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<tr>
<td><strong>Variable</strong></td>
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<tr>
<td><strong>Outreach events</strong></td>
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<tr>
<td>Educational presentations</td>
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<tr>
<td>Special events and health fairs</td>
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<td><strong>Community members receiving information or education</strong></td>
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<tr>
<td>Individuals</td>
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<td>Groups</td>
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<tr>
<td>Estimated participants at annual conference</td>
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<tr>
<td><strong>Community members receiving client services</strong></td>
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<tr>
<td>Referred and supported for mammography screening</td>
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<tr>
<td>Help with interpretation</td>
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<tr>
<td>Help with transportation</td>
</tr>
<tr>
<td>Mammograms completed</td>
</tr>
<tr>
<td>Clinical breast examinations</td>
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<tr>
<td>Breast cancers detected (various stages)</td>
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<tr>
<td><strong>Breast cancer survivors receiving support</strong></td>
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<td>Breast cancer survivors participating in Triunfadoras</td>
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<td>New members of Triunfadoras</td>
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<td>Survivors receiving Entre Amigas home visits</td>
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treatment and follow-up visits with medical providers. Entre Amigas program staff call all active participants monthly to maintain contact and assess for unmet needs and barriers. Twenty survivor promotoras have been trained since the program was initiated in 2010. The program was funded by the Susan G. Komen Foundation and the Livestrong Foundation.

Program Evaluation

To evaluate the program, researchers from the College of Nursing at the University of Utah collaborated with program staff to systematically review five years (2009–2013) of program data. The study included a reliance agreement and was approved by the institutional review board at the University of Utah. Staff created de-identified versions of each database and report and provided these to the research team for analysis. These data sources included the following:

- Monthly and annual program reports that include descriptions of program activities and summaries of events and contacts. Data were related to community outreach activities, including type of event and number attended. The unit of analysis is the event.
- A database of women attending outreach events who were interested in mammography screening and were supported in the process of receiving a clinical examination and mammogram. Variables included services provided and date of completion of the examination and screening. The unit of analysis is the individual women to be screened.
- A database of the cancer survivors who participate in Triunfadoras. This database captures demographic and clinical data on each person who has ever been referred to and/or participated in Triunfadoras and Entre Amigas.
- An annual survey that evaluates participant satisfaction with Triunfadoras. Structured questions address program participation and satisfaction with specific program components. Sources of dissatisfaction are solicited in comment fields.

Analysis included summary statistics (frequencies, percent, means, and standard deviations) of key measures, annually and cumulatively, during the five-year period.

Findings

The accomplishments since 2009 are summarized in Table 1. Services were provided for women aged 30–70 years whose time since diagnosis varied from a new diagnosis to more than 10 years since first diagnosis. In addition to breast cancer survivors, the program provided services to more than 60 community members with other types of cancers. The majority of the women with breast cancer are from Mexico (n = 148, 55%), but the program has successfully included women from countries in Central America (n = 20, 7%), South America (n = 67, 25%), and other areas such as the Caribbean and Spain (n = 8, 3%).

Engagement in the support group was high, with monthly attendance ranging from 20–50 survivors. Some survivors traveled as many as 50 miles to attend the group. Many women brought family members, including parents, spouses, or children. Some survivors have maintained their participation since the group was founded in 2002. From 2008–2012, the annual satisfaction survey indicated that more than 90% rated the role of the group, the emotional support provided, and the quality of the presenters and resources as good or excellent. The survey was revamped in 2013. Findings are summarized in Figure 1. Survey comments supported these ratings.

The Entre Amigas program staff called 50 or more active participants on a monthly basis to screen for unmet needs. They provided home visits to 86 Hispanic women with breast cancer. Many needs have been identified, including financial support, transportation to attend support group meetings or medical assistance, babysitting or childcare, psychological assistance, and communication skill-building tools to better communicate with family, caregivers, or healthcare providers.

Discussion

The ABC program is a thriving intervention that addresses local, cultural, and family-based needs and expectations, spanning the
successes of the continuing needs assessed by the support groups and other community partners. Each of the three component programs has uniquely contributed to this success. The outreach and screening program has effectively collaborated with community partners to provide mammography and breast examinations to underserved women. Data evaluations from the UCCP report that the number of women screened for breast cancer who declared being of Hispanic ethnicity climbed from 35% in 2005 to 56% in 2014. The impact of the outreach and screening program is substantial, as a total of 612 “new” women reported being referred by a navigator.

Triunfadoras is meeting a community need, as evidenced by its growth and sustainability. The program membership has grown from 10 initial survivors to more than 300 participants, including a group whose participants have other types of cancer. There is a high level of satisfaction with the support group. Triunfadoras is similar to the educational and supportive nature provided in other support programs. However it is unique in that it reaches Hispanic women from many different countries of origin, allows attendance by family members (which is consistent with cultural values), and provides a sense of community. Each of the participants, including a group whose participants have other types of cancer.

Challenges

Despite the program’s many successes, the authors discovered a need for additional resources. Emotional and mental health counseling is needed to address health concerns, such as moderate to severe depression, anxiety, and distress, in some women. A greater need exists for survivorship care planning and self-care management. Support services could focus on male partners, family members, and caregivers, particularly when the woman with cancer faces a terminal diagnosis (see Figure 2). In addition, the program could be expanded to meet the needs of Hispanics in other counties in Utah.

Of note is the high percentage of women needing transportation and interpretation services to receive screening. These data are consistent with other reports that suggest that these factors are major barriers to screening in Hispanic women (Alexandraki & Mooradian, 2010). Like many community-based programs, the ABC program must seek long-term sustainability options to expand its services and continue to meet the needs of the women in the program.

Conclusion

Community-based interventions should be culturally tailored to the specific populations they are attempting to serve. The ABC program is effective because it is grounded in the cultural values and traditions of the participants. Each of the three component programs has uniquely contributed to this success. The outreach and screening program has effectively collaborated with community partners to provide mammography and breast examinations to underserved women. Data evaluations from the UCCP report that the number of women screened for breast cancer who declared being of Hispanic ethnicity climbed from 35% in 2005 to 56% in 2014. The impact of the outreach and screening program is substantial, as a total of 612 “new” women reported being referred by a navigator.

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serve. These interventions are highly effective when they address personal preferences, eliminate barriers, include trained peer navigators or community health workers, and offer education as well as psychosocial support services for patients and family (Paskett, Harrop, & Wells, 2011; Weber, Mascarenhas, Bellin, Raab, & Wong, 2012). The ABC program shows how members of one community forged partnerships to address health disparities and community needs in a culturally tailored manner. The program serves as a model to other communities trying to improve cancer screening, detection, and supportive services for specific populations and has the potential to improve quality of life and long-term outcomes.

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References


