Recruitment and Retention Strategies of African American and Latina American Breast Cancer Survivors in a Longitudinal Psycho-Oncology Study

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Research participation is crucial for accessing data and scientific knowledge to advance medical care and reduce health disparities. Ethnic minorities (e.g., African Americans, Latino Americans) comprise about 30% of the U.S. population (U.S. Census Bureau, 2012); however, they remain underrepresented in health research (Ashing-Giwa, 2005a; Ford et al., 2008; Institute of Medicine, 2008, 2009; Wendler et al., 2006; Yancey, Ortega, & Kumanyika, 2006). Despite the National Institutes of Health (2001) 1993 Revitalization Act that mandated the inclusion of ethnic minorities in research, underrepresentation in health research persists.

Advancement toward reducing health disparities is hampered by knowledge gaps because of the inadequate inclusion of ethnic minorities in health-related research (Farmer, Jackson, Camacho, & Hall, 2007; Topp, Newman, & Jones, 2008; Yancey et al., 2006). Low participation can be attributed to several dynamics, including investigatory, cost, historical, and personal factors. For example, not inviting ethnic minorities to participate in research (Evelyn et al., 2001; Hatchett, Holmes, Duran, & Davis, 2000; Nicholson et al., 1999; Portillo et al., 2001; Wendler et al., 2006), the lack of culturally and linguistically responsive protocol and staff and adequately trained staff (Ashing-Giwa, 2005a, 2005b; Giuliano et al., 2000), and protocol demands are noted barriers. In addition, limited English-proficient groups are excluded to avoid costs and translation (Hahn & Cella, 2003; Hahn et al., 2010). Regarding sociohistorical factors, research mistrust and lack of community acceptability still prevail (Shavers, Lynch, & Burmeister, 2002; Wendler et al., 2006; Yancey et al., 2006). On the individual or personal level, research participation concerns among ethnic minorities include knowledge of the research process, practical issues (e.g., transportation, work and family interference, participation requirements) (Du, Valenzuela, Diaz, Cella, & Hahn, 2008; Ford et al., 2005), and cultural elements (e.g., religious and health beliefs) (Brown, Fouad, Basen-Engquist, & Tortolero-Luna, 2000; Comis, Miller, Aldigé,
Ethnic minorities are underrepresented in most realms of cancer research, including survivorship and psychosocial studies (McIlvane, Baker, Mingo, & Haley, 2008; Mishel et al., 2005). However, for intervention studies to have greater societal impact, they must reach ethnic minority populations and make every effort to include representative populations (Hiatt et al., 2001; McIlvane et al., 2008; Sandgren & McCaul, 2003), which unfortunately remains a challenge in health research.

This article presents the recruitment and retention strategies and outcomes of a longitudinal intervention study designed to improve the health-related quality of life (HRQOL) of African American and Latina American breast cancer survivors (BCSs). The original research tested the efficacy of a telephone-based behavioral intervention trial delivered by trained clinical research assistants (CRAs) to improve well-being and HRQOL.

**Methods**

**Participants**

Participants were women 18 years of age and older, self-identified as African American or Latina American, within one to six years of a breast cancer diagnosis and postprimary treatment, diagnosed with stage 0–III breast cancer, and not diagnosed with any other type of cancer. BCSs residing in southern California were recruited from the California Cancer Registry (CCR), the registries from two National Cancer Institute–designated comprehensive cancer center hospitals in California, and community agencies (e.g., support groups).

**Measures**

The self-report assessments included demographic variables (e.g., age, income), medical factors (e.g., stage, years since diagnosis), and standardized measures (i.e., Functional Assessment of Cancer Therapy for patients with breast cancer [FACT-B] for assessing HRQOL, the SF–36, the Medical Outcomes Survey Social Support Scale for assessing availability of social support, and the Life Stress Scale for assessing life burden from different life domains) (Ashing-Giwa, Ganz, & Petersen, 1999; Cella, 1997; Hays, Sherbourne, & Mazel, 1993, 1995).

**Procedure**

Participant recruitment and enrollment strategies: BCSs in California were recruited from the population-based CCR, hospital cancer registries, and community agencies (e.g., support groups) to increase the number of ethnic minority BCSs participating. City of Hope National Medical Center institutional review board approval was obtained, and all participants verbally consented to be screened for study eligibility and signed a written consent to participate in the study. The study approach was guided by the Contextual Model of HRQOL (Ashing-Giwa, 2005b) and the Culturally Responsive Model of Research Design (CRMRD) (Ashing-Giwa, 2005a).

**Study approach and guiding principles:** The theoretical and analytical foundation of this study is the Contextual Model of HRQOL (Ashing-Giwa, 2005b; Ashing-Giwa & Lim, 2008; Ashing-Giwa, Tejero, Kim, Padilla, & Hellemann, 2007). The model was developed by quantitative and qualitative outcomes research that included ethnically and linguistically diverse and population-based samples (Ashing-Giwa et al., 2007). In the Contextual Model of HRQOL, HRQOL is shaped by two components, individual-level and systemic-level factors. Individual-level factors are comprised of medical factors (e.g., cancer characteristics, age at diagnosis, years since diagnosis), general health status, and psychological well-being. Systemic-level factors include socioeconomic factors, healthcare system, cultural context, and demographic information. The model also assumes the mediating effects of individual-level factors in the relationship between systemic-level factors and HRQOL outcomes (Ashing-Giwa & Lim, 2008), such that systemic-level factors may have a positive effect on individual-level factors, which then may improve HRQOL (Holmbeck, 1997; MacKinnon & Fairchild, 2009). The model promises broader application and is used in the current study as a framework to appreciate the contextual or lived experience of the target population. The cultural climate of the current study was participant-centered and further guided by the CRMRD. The study staff participated in a two-week preparatory training and ongoing weekly or biweekly training and supervision that advanced the uptake and application of the CRMRD guiding principles and practices: (a) language competency, (b) cultural competency (i.e., knowledge and sensitivity for the cultural origins and context of the survivor), (c) ethical conduct (i.e., high degree of professionalism and respect), (d) empathy (i.e., instilling community-minded and patient-centered practices), (e) credibility (i.e., a well-trained staff with basic knowledge about risk, screening, and treatment; more in-depth training on the human impact of the illness; and available resources [e.g., local, national, Web-based, governmental]), (f) purpose (i.e., a belief that the knowledge and findings from the study can offer important scientific and community benefit), (g) graciousness (i.e., sincere gratitude is expressed to each survivor who shares her cancer experience), and (h) protocol proficiency. Therefore, all participant interactions were responsive, respectful, and caring. The CRMRD approach informed the specific protocol described in this article.

**Participant invitation:** After obtaining potential eligible participants from the CCR and other cancer registries, the recruitment process involved mailing letters...
A recruitment letter (in English or Spanish) describing the study was mailed to all potential participants after physicians were contacted. The letter described the study purpose, participant involvement, and confidentiality. Participants were instructed to contact the toll-free telephone number provided if they were interested in participating or if they had any questions or concerns. That protocol involving an initial mailed invitation to participate in the research study demonstrated respect via a formal notification and ethical compliance with registry protocol. However, ethnic minority populations generally do not respond in large enough numbers to mailed surveys (Ashing-Giwa, Padilla, Tejero, & Kim, 2004; Hahn et al., 2010). Therefore, if the participant did not respond within two weeks following the mailed survey, a trained ethnically and linguistically matched CRA contacted the participant via telephone. The CRAs made, on average, seven phone calls to each BCS before classifying them as inaccessible. When BCSs called the toll-free number or the CRA contacted them, a script for screening, consenting, and enrolling the potential participants was followed. The script guided the CRA on how to assess (e.g., caller inquiries about study, concerns, ineligibility) and how to proceed with the call. Each participant was assigned a linguistically competent CRA based on the potential participant’s ethnicity; every attempt was made so that all telephone contact was conducted by one CRA. Credibility and trust were fostered for every telephone conversation with a linguistic and culturally competent CRA who practiced the study’s eight guiding principles (Ashing-Giwa, 2005b). BCSs who agreed to be screened were assessed for study eligibility, and enrollment took place during the telephone conversation. If a participant was ineligible, a different script was followed by the CRA. Every effort was made to be clinically responsive (i.e., responding to any clinical-related questions participants may have had by providing additional information and resources), even with ineligible BCSs. For example, if a BCS requested information on advanced cancer, the CRA provided useful resources (e.g., printed, telephone, Web-based).

**Participant enrollment:** The telephone enrollment protocol accomplished the following: (a) presentation and discussion of the purpose of the study and informed consent; (b) clarification of any preliminary questions and concerns of potential participants; and (c) established personal contact, a key factor in the recruitment and enrollment of ethnic minorities. Eligible participants then were mailed a packet that included a personalized welcome letter, two copies of the consent form, the baseline assessment survey, and a self-addressed, stamped return envelope. The baseline survey, available in English or Spanish, took about 60 minutes to complete and participants were given three weeks to return the completed survey and signed consent form. After completion of the survey, participants were assigned to the behavioral trial if they agreed to participate or if they had any questions or concerns.

### Recruitment Outcomes for African American and Latina American Breast Cancer Survivors

<table>
<thead>
<tr>
<th>Registry Accessible</th>
<th>Registry Ineligible</th>
<th>Registry Eligible</th>
<th>Community Available</th>
<th>Deceased</th>
</tr>
</thead>
<tbody>
<tr>
<td>AA = 115 (24%)</td>
<td>AA = 11 (2%)</td>
<td>AA = 104 (21%)</td>
<td>AA = 58 (56%)</td>
<td>AA = 4 (&lt; 1%)</td>
</tr>
<tr>
<td>L = 481 (36%)</td>
<td>L = 111 (8%)</td>
<td>L = 370 (27%)</td>
<td>L = 46 (44%)</td>
<td>L = 23 (2%)</td>
</tr>
<tr>
<td>U = 18 (49%)</td>
<td>U = 9 (24%)</td>
<td>U = 9 (24%)</td>
<td>U = 9 (24%)</td>
<td>U = 9 (24%)</td>
</tr>
<tr>
<td>Total = 614 (33%)</td>
<td>Total = 131 (7%)</td>
<td>Total = 483 (26%)</td>
<td>Total = 104</td>
<td>Total = 27 (1%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Available Population</th>
<th>Registry Eligible</th>
<th>Registry Ineligible</th>
<th>Deceased</th>
</tr>
</thead>
<tbody>
<tr>
<td>AA = 162 of 546 (30%)</td>
<td>AA = 104 (21%)</td>
<td>AA = 11 (2%)</td>
<td>AA = 4 (&lt; 1%)</td>
</tr>
<tr>
<td>L = 416 of 1,403 (30%)</td>
<td>L = 370 (27%)</td>
<td>L = 111 (8%)</td>
<td>L = 23 (2%)</td>
</tr>
<tr>
<td>U = 9 of 37 (24%)</td>
<td>U = 9 (24%)</td>
<td>U = 9 (24%)</td>
<td>U = 9 (24%)</td>
</tr>
<tr>
<td>Total = 587 of 1,986 (30%)</td>
<td>Total = 483 (26%)</td>
<td>Total = 131 (7%)</td>
<td>Total = 27 (1%)</td>
</tr>
</tbody>
</table>

AA—African American; L—Latina American; U—unknown or other.

**Figure 1. Recruitment Outcomes for African American and Latina American Breast Cancer Survivors**

Describing the study to treating physicians, along with a list of their potential patients for study inclusion. That letter complied with the CCR and hospital registries’ procedures and allowed physicians to exclude women who were ineligible because of their cancer status or comorbidities; of note, no BCS was excluded by her physician. A recruitment letter (in English or Spanish) describing the study was mailed to all potential participants after physicians were contacted. The letter described the study purpose, participant involvement, and confidentiality. Participants were instructed to contact the toll-free telephone number provided if they were interested in participating or if they had any questions or concerns.

### Participant recruitment and screening

When BCSs called the toll-free number or the CRA contacted them, classifying them as inaccessible.
to eight weekly telephone interventions plus survivorship materials or survivorship materials only. All the information for continued participation was conveyed both via telephone, for continuity of study contact, and by mail, for verification. During the study continuation call, participants again were oriented to the study purpose, the nature of their involvement, the assignment process, and the details of the intervention conditions.

**Participant retention:** Very careful attention was paid to participants’ needs and overall retention issues during ongoing training and supervision. Therefore, participant letters were crafted carefully; these letters communicated the necessary information in a clear, culturally sensitive, linguistically uncomplicated, and brief presentation. The letters could be modified by the CRA to create a more participant-centered communication. In addition, the CRAs were diligent, responsive, and nurturing in all their communications with the participants. A follow-up response was provided to every participant’s request or issue whether they communicated via writing or telephone. All trial participants received compensation for their time and completion of the assessments. To enhance retention, all trial participants received a reminder telephone call regarding the forthcoming postbaseline assessment survey.

**Data collection:** Assessments took place at baseline after entry into the study and at 4–6 months postbaseline. The assessments were in the form of self-report, written survey instruments. After completion of the baseline survey, participants received a $20 grocery store gift card, and a $40 gift card after completion of the postbaseline survey.

## Results

### Recruitment

In total, 1,882 initial recruitment letters were mailed to potential participants (see Figure 1). Among those potential participants, 614 (33%) were able to be contacted. Among the 614 cases recruited from the CCR and hospital registries, 7% were ineligible for the study; the most common explanation was medical reasons (e.g., severe comorbidities, recurrence), followed by being in active treatment at the time of the study, being less than a year postdiagnosis, or being more than six years postdiagnosis. Z tests were conducted to examine whether accessibility and eligibility varied by ethnic group membership. A significant difference existed among registry participants, as 36% of Latina Americans and 24% of African Americans were able to be contacted ($z = 4.75, p < 0.001$). In addition, a significant ethnic difference existed for eligibility, as 8% of Latina Americans and 2% of African Americans were ineligible ($z = 4.41, p < 0.001$).

In addition, a subgroup of the available population was recruited through a support group or community agency, of which 58 participants were African American and 46 were Latina American. Among the overall available potential cases, 43% ($n = 251$) were obtained from the CCR, 44% ($n = 223$) were ascertained from hospital registries, and 13% ($n = 104$) were recruited from community agencies. Thus, the total available population equaled 587, with 28% being African Americans and 71% Latina Americans.

### Participation

In total, 468 BCSs (80% of total available population) agreed to participate (see Figure 2). African American BCSs were more likely to agree to participate (90%) than Latina Americans BCSs (77%). Overall, 375 BCSs were enrolled and completed the baseline survey, constituting a 64% participation rate of the available population. In addition, 320 BCSs finished the entire study by completing the follow-up survey, a 55% overall participation rate of the available population and a 68% participation rate of the BCSs who agreed to participate. Among the available population, 119 (20%) BCSs refused to participate. In regard to other recruitment challenges, 20% of the...
eligible participants were nonresponders (i.e., agreed during screening but did not return the baseline survey), and 9% of the responders were incomplete-responders (i.e., did not return follow-up survey).

Z tests for two proportions were conducted to test for significant differences across ethnic groups among participants who completed the baseline survey and those who completed both baseline and follow-up surveys. Significant ethnic differences emerged for the proportion who completed the baseline; 73% of African American BCSs who consented completed the baseline versus 62% of Latina American BCSs (z = 2.4, p = 0.016). However, no significant ethnic difference in the proportions existed for the follow-up survey, as 56% of Latinas and 54% of African Americans completed the follow-up survey (z = 0.22, p = 0.82).

**Demographic and Disease Characteristics**

In total, 320 (88 African American and 232 Latina American) BCSs completed the follow-up survey. A total of 119 BCSs took part in the telephone sessions plus survivorship materials group and 201 BCSs were in the survivorship materials–only group. Demographic characteristics are described in Table 1. The majority of the BCSs had at least a high school education and more reported a yearly income of $25,000 or less than any other income level. Significant differences in demographic characteristics included Latinas being more likely to report being born outside the United States, reporting lower education levels and household income, and being less likely to work outside the home; African American BCSs were more likely to be unpartnered. Disease characteristics are described in Table 2. The population was primarily a cohort of early-stage, disease-free, and lower-income BCSs.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total Sample (N = 320)</th>
<th>African American (N = 88)</th>
<th>Latina American (N = 232)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>X</td>
<td>SD</td>
<td>X</td>
</tr>
<tr>
<td>Birth country</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>United States</td>
<td>143</td>
<td>45</td>
<td>85</td>
</tr>
<tr>
<td>Other</td>
<td>164</td>
<td>51</td>
<td>2</td>
</tr>
<tr>
<td>No response</td>
<td>13</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Relationship status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partnered</td>
<td>171</td>
<td>53</td>
<td>37</td>
</tr>
<tr>
<td>Unpartnered</td>
<td>140</td>
<td>44</td>
<td>51</td>
</tr>
<tr>
<td>No response</td>
<td>9</td>
<td>3</td>
<td>–</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>108</td>
<td>34</td>
<td>4</td>
</tr>
<tr>
<td>High school or more</td>
<td>201</td>
<td>63</td>
<td>84</td>
</tr>
<tr>
<td>No response</td>
<td>11</td>
<td>3</td>
<td>–</td>
</tr>
<tr>
<td>Income ($)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 25,000</td>
<td>149</td>
<td>47</td>
<td>27</td>
</tr>
<tr>
<td>25,000–44,999</td>
<td>70</td>
<td>22</td>
<td>26</td>
</tr>
<tr>
<td>45,000–75,000</td>
<td>40</td>
<td>13</td>
<td>16</td>
</tr>
<tr>
<td>More than 75,000</td>
<td>51</td>
<td>16</td>
<td>18</td>
</tr>
<tr>
<td>No response</td>
<td>10</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Homemaker</td>
<td>111</td>
<td>35</td>
<td>16</td>
</tr>
<tr>
<td>Service</td>
<td>44</td>
<td>14</td>
<td>10</td>
</tr>
<tr>
<td>Operator</td>
<td>12</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Technical</td>
<td>52</td>
<td>16</td>
<td>17</td>
</tr>
<tr>
<td>Professional</td>
<td>72</td>
<td>23</td>
<td>31</td>
</tr>
<tr>
<td>Other</td>
<td>20</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>No response</td>
<td>9</td>
<td>3</td>
<td>–</td>
</tr>
</tbody>
</table>

* p < 0.05; **p < 0.01

**Note.** Because of rounding, not all percentages total 100.

**Discussion**

Ethnic minorities are underrepresented in health research (Ashing-Giwa, 2005a; Giuliano et al., 2000; Wendler et al., 2006; Yancey et al., 2006). In addition, when they do take part in research, their participation rates are much lower than those of European Americans (Evelyn et al., 2001; Moreno-John et al., 2004; Portillo et al., 2001; Powell & Fleming, 2000; Stark et al., 2002; Stull, Snyder, & Demark-Wahnefried, 2007). In a preliminary examination of the literature, the authors estimated 15%–20% of the participants in intervention studies were from ethnic minority populations (Evelyn et al., 2001; Moreno-John et al., 2004; Portillo et al., 2001; Powell & Fleming, 2000; Stark et al., 2002; Stull et al., 2007). The inclusion of ethnic minorities in research is required when conducting population-based research and for the attainment of equitable health outcomes for all.

The current study’s findings demonstrated that more than 33% of Latina American BCSs were accessible compared to 25% of African American BCSs. However, Latina American BCSs were less eligible (because of disease and psychological status) compared to their African American counterparts (8% versus 2%, respectively). Overall, the current study’s recruitment efforts yielded a more favorable African American survey completion rate at baseline compared to Latinas (76% versus 61%, respectively). However, at follow-up, no ethnic differences were observed in overall study completion, with both groups completing the entire study at a rate of 54% or greater. These outcomes suggest that very special attention must be paid to the initial recruitment of Latinos to engage their interest and participation. For
African Americans, particular attention must be devoted to their retention to address attrition.

**Lessons Learned**

Recruitment outcomes are influenced by participant and study characteristics. The rates of participation in cancer trials are particularly low among ethnic minorities, and evidence exists that participation has decreased in these and other studies in recent years (Baquet, Ellison, & Mishra, 2009; Du, Mood, Gadgeel, & Simon, 2009; Evelyn et al., 2001; Galea & Tracy, 2007; Moreno-John et al., 2004; Schmotzer, 2012). The current study’s process and outcomes suggest that successful study characteristics require targeted culturally and socioecologically informed recruitment and retention strategies, including staffing issues (e.g., characteristics [i.e., empathy], cultural and linguistic competency, selection, training, supervision) and overall study approach, protocol, and site or recruitment source to address barriers to participation.

**Study site or recruitment source**: The findings demonstrate that the recruitment source impacted the availability and accessibility, as well as enrollment outcomes. The cases obtained from major cancer center hospital registries yielded a greater response compared to the population-based registry. The state cancer registries represent the avenue for population-based case ascertainment; however, only 19% of the cases identified via CCR data were reachable and, therefore, available for inclusion. Similar outcomes have been reported for other registry-based studies (Ashing-Giwa et al., 2004; McCorkle, Tang, Greenwald, Holcombe, & Lavery, 2006).

**Approach**: Implementing a culturally and socioecologically informed and participant-centered study approach was effective in guiding successful recruitment and retention strategies and outcomes of the available or reachable cases. Recruitment from cancer registries allows access to a population-based sample; however, the reach can be low. In addition, ethnic minorities are a hard-to-reach population because of several factors (e.g., age, educational attainment, distance, recruiting site [e.g., public hospital], income, language) (Du et al., 2008). Therefore, given the demographics of the current population, the drop-out rate was not significant. In addition, only 9% of participants did not complete the follow-up. Thus, a key factor of the recruitment outcomes may be attributed to anchoring the study in a culturally and socioecologically informed approach outlined by the CRMRD (Ashing-Giwa, 2005a). As the sampling method can be limiting, mixed-method sampling was employed, and BCSSs were recruited from several sites to maximize recruitment. Another strategy outlined by the CRMRD is multilevel invitations to participation—first a mailing, followed by telephone contact from a trained CRA. The initial invitational mailing introduced the study through the use of culturally relevant information (e.g., cancer survivorship in minority women) (Ashing-Giwa, 2005a). In terms of recruitment, persistence and cultural proficiency are crucial staffing characteristics (Eakin et al., 2007; Levkoff & Sanchez, 2003). These studies concur with the CRMRD and highlight the importance of study staff members who are engaging, personable, and able to relate to potential participants, facilitating trust and participation. Staff language proficiency also is required, so Spanish-speaking staff members were available to work with monolingual Spanish-speaking BCSSs. In addition, CRAs were available during flexible hours, including mornings and late evenings.

Staff preparedness was enhanced by preassessment and ongoing training on the eight principles for participant safety and monitoring outlined by the CRMRD. The intensive staff training in basic breast cancer and HRQOL information, study protocol, ethical conduct, and community-minded and patient-centered orientation contributed to the competency of the research staff (Ashing-Giwa, 2005a), increasing staff

### Table 2. Participant Disease Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total Sample (N = 320)</th>
<th>African American (N = 88)</th>
<th>Latina American (N = 232)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stage</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>17 5</td>
<td>6 7</td>
<td>11 5</td>
</tr>
<tr>
<td>II</td>
<td>119 37</td>
<td>34 39</td>
<td>85 37</td>
</tr>
<tr>
<td>III</td>
<td>126 39</td>
<td>32 36</td>
<td>94 41</td>
</tr>
<tr>
<td>No response</td>
<td>52 16</td>
<td>14 16</td>
<td>38 16</td>
</tr>
<tr>
<td><strong>How lump was detected</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical examination</td>
<td>140 44</td>
<td>45 51</td>
<td>95 41</td>
</tr>
<tr>
<td>Breast self-examination</td>
<td>170 53</td>
<td>42 48</td>
<td>128 55</td>
</tr>
<tr>
<td>No response</td>
<td>10 3</td>
<td>1 1</td>
<td>9 4</td>
</tr>
<tr>
<td><strong>Surgery</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mastectomy</td>
<td>190 59</td>
<td>63 72</td>
<td>127 57</td>
</tr>
<tr>
<td>Mastectomy plus immediate reconstruction</td>
<td>120 38</td>
<td>29 33</td>
<td>91 41</td>
</tr>
<tr>
<td>Other treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>213 67</td>
<td>51 58</td>
<td>162 70</td>
</tr>
<tr>
<td>Radiation</td>
<td>222 69</td>
<td>59 67</td>
<td>163 70</td>
</tr>
<tr>
<td>Hormone therapy</td>
<td>207 65</td>
<td>53 60</td>
<td>154 66</td>
</tr>
<tr>
<td><strong>Other medical conditions</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>117 37</td>
<td>43 47</td>
<td>74 39</td>
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<td>76 33</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>44 14</td>
<td>7 9</td>
<td>37 16</td>
</tr>
<tr>
<td>Psychological difficulties</td>
<td>92 29</td>
<td>13 15</td>
<td>79 34</td>
</tr>
</tbody>
</table>

*Participants selected all that applied.*

**Note.** Because of rounding, not all percentages total 100.
credibility and study enrollment outcomes. Ongoing bi-
weekly supervision and training also were incorporated.
In addition, the staff was well informed about a variety of
community resources, including legal resources, social
services, and supportive care services, to make the ap-
propriate patient and clinically responsive referral.

Limitations

The recruitment of participants from population-
based sources such as state cancer registries still leaves
many challenges. The CCR cases available for inclusion
equaled only 21% of the total potential African American
cases and 27% of the total potential Latina American
cases. The inaccessibility of potential cases was primar-
ily from incorrect contact information. Many survivors
changed residences over time, given that these survivors
were contacted one to six years post-treatment. One
strategy to improve the accuracy of the state registry
contact information is to access the cases via the rapid
case ascertainment (RCA) process, which allows for
the inclusion of cases less than a year after diagnosis.
However, the RCA process may be prohibitive for some
studies because the cost is at least three-fold of the
normal cost of about $1,000. In addition, RCA does not allow
for investigations with long-term survivors, as the cases
usually are limited to less than two years postdiagnosis.
Training for the RCA process is both time intensive and
potentially costly, but studies that are well designed and
implemented may outweigh the costs and contribute to
the Institute of Medicine’s call for the inclusion of ethnic
minorities and women in research.

Another limitation is the participation rate, as 20% of
the BCSs from the available population refused to partici-
rate, 16% of the BCSs were classified as nonresponders,
and 9% of the respondents were incomplete-responders
(i.e., did not return follow-up survey). In addition, the
proportion of African Americans in the study is of po-
tential concern. African Americans accounted for 28%
of the available population and 28% of the total study
sample. This lower proportion is representative of the
African American population in California. Overall, the
findings document success in the recruitment (76% Af-
rican American and 61% Latina American), and reten-
tion (54% African American and 56% Latina American)
of mostly lower-income BCSs, as these rates are similar
to those reported in prior research (Galea & Tracy, 2007;
Schmotzer, 2012). However, additional studies are
necessary to identify more strategies to increase their
successful inclusion in research.

Conclusion

Conducting intervention studies with ethnic minor-
ity populations presents certain recruitment challenges,
which is particularly true given the limited literature of-
fering practical guidelines for successful ethnic minority
inclusion and participation in research, including behav-
ioral interventions. This article presents the process and
outcomes of implementing a culturally, linguistically, and
socioecologically responsive investigational approach
to enhance ethnic minority participation in research.
Therefore, if one of the stated aims of the study is ethnic
and linguistic minority inclusion, cultural sensitivity
staff training is conducted along with regular supportive
supervision, and investments in recruitment strategies
are implemented (e.g., language and presentation of the
study documents), so the participant diversity target (i.e.,
anticipated sample size for ethnic minority participants)
can be met. For example, the application of these over-
arching strategies proved successful in other behavioral
studies of Latino survivors (Ashing-Giwa, 2008; Ashing-
Giwa et al., 2007)

In summary, the findings from this study emphasized
that successful recruitment and retention of ethnic mi-
orities into population research requires thoughtful
appreciation and detailed, planned efforts to address the
personal and contextual factors. In addition, the
study-related barriers should be considered to maximize
the inclusion of underserved and underrepresented
populations (Ashing-Giwa, 2005a, 2005b; Ashing-Giwa
et al., 2004; Ashing-Giwa et al., 2009; Brown et al., 2000).

Implications for Nursing

Nursing research and practice have championed the
inclusion of ethnic minorities in survivorship studies,
but adequate enrollment of underrepresented groups
remains a challenge. To address health disparities and
increase the applicability of healthcare research to a
diverse population, researchers must develop and imple-
ment effective ways to recruit, enroll, and retain diverse
participants. This article outlines a proposed strategy
for the inclusion of population-based samples and the
inclusion of ethnic minority and lower-income survivors.

The authors gratefully acknowledge all the survivors who shared
their experiences by participating in this study, as well as Alejan-
dro Fernandez, BA, for his contributions to the data management
and analyses.

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search Institute and a founding director of the Center of Com-
munity Alliance for Research and Education in the Depart-
ment of Population Sciences, and Monica Rosales, PhD, is a re-
search fellow at the Center of Community Alliance for Research
and Education in the Department of Population Sciences, both at
City of Hope National Medical Center in Duarte, CA. This study
was supported by a grant from the Department of Defense–
Breast Cancer Research Program (W81XWH-04-1-0548). Ash-
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editor at ONFEditor@ons.org. (Submitted September 2011.
Accepted for publication January 7, 2012.)

Digital Object Identifier: 10.1188/12.ONF.E434-E442
References


