

© 2012 by the Oncology Nursing Society. Unauthorized reproduction, in part or in whole, is strictly prohibited. For permission to photocopy, post online, reprint, adapt, or otherwise reuse any or all content from this article, e-mail pubpermissions@ons.org. To purchase high-quality reprints, e-mail reprints@ons.org.

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

Kimlin Ashing-Giwa, PhD, and Monica Rosales, PhD

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,

Purpose/Objectives: To describe recruitment and retention strategies of a psychosocial intervention with African American and Latina American breast cancer survivors (BCSs).

Design: Prospective design with pre- and post-testing.

Setting: A mailed survey and assignment to telephone counseling or education booklet only.

Sample: 587 African American and Latina American BCSs were recruited.

Methods: The sample was drawn from the population-based California cancer and hospital registries, as well as community agencies. Mailed self-report health-related quality-of-life assessments were at baseline and 4–6 months follow-up.

Main Research Variables: Accrual outcomes; recruitment and retention strategies.

Findings: A total of 375 (64%) completed the baseline survey and 320 (55%) completed both baseline and follow-up assessments. The recruitment outcomes suggest that very special attention must be paid to the initial recruitment of Latina Americans to engage their interest and participation. For African Americans, particular attention must be devoted to their retention to address potential attrition.

Conclusions: Findings suggest that the inclusion of lower-income and ethnic minority cancer survivors in a longitudinal intervention study is doable. The results indicate that recruitment outcomes are influenced by participant and study characteristics. Successful enrollment requires investigations that attend to culturally and socioecologically informed recruitment and retention strategies, from staff selection, training, and supervision to overall study approach protocol, to address barriers to participation.

Implications for Nursing: Nursing research and practice have championed survivorship care, including psychosocial care. This article outlines practical strategies to recruit and retain population-based samples, ethnic minorities, and underserved survivors.

& 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,

Krebs, & Stoval, 2003; Elish, Scott, Royak-Schaler, & Higginbotham, 2009; Giuliano et al., 2000; Topp et al., 2008; Yancey et al., 2006).

Ethnic minorities are unrepresented 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).

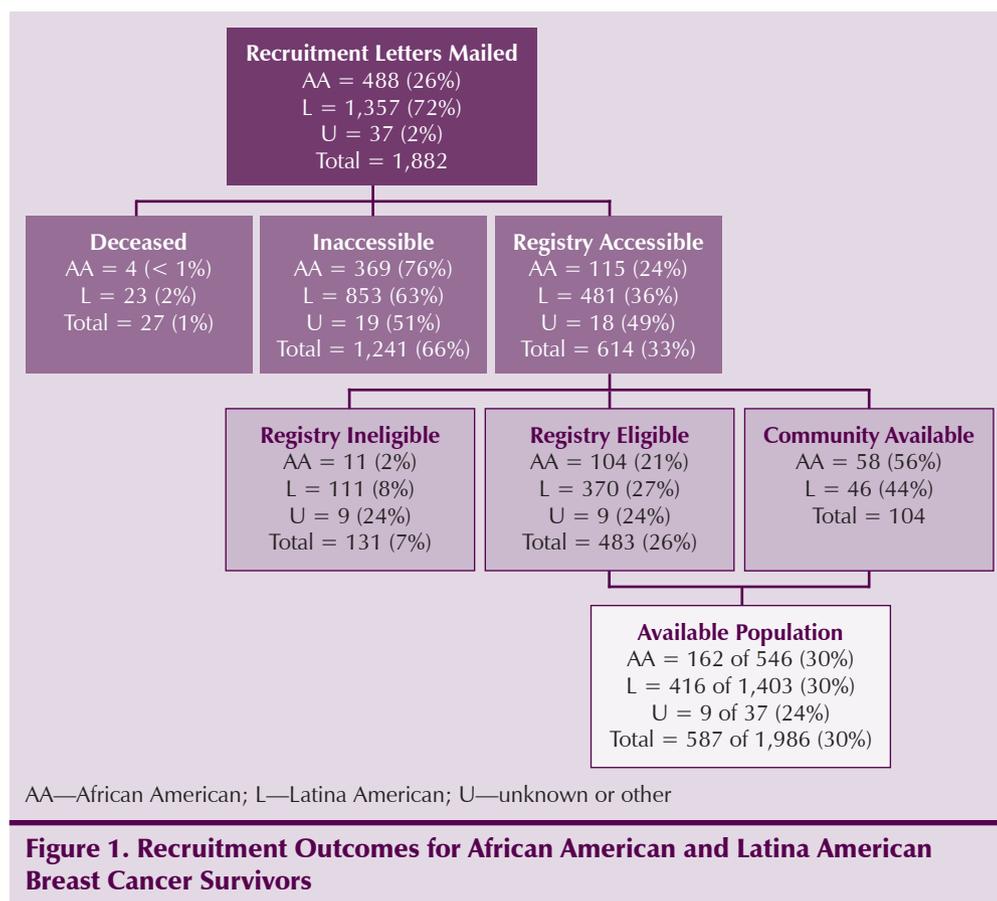
Procedure

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 (CRM RD) (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 socioecologic 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 CRM RD. 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 CRM RD 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 CRM RD 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



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 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.

Participant recruitment and screening: 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 reported a moderate to severe level of burden on the FACT-B. The intervention conditions consisted of six

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

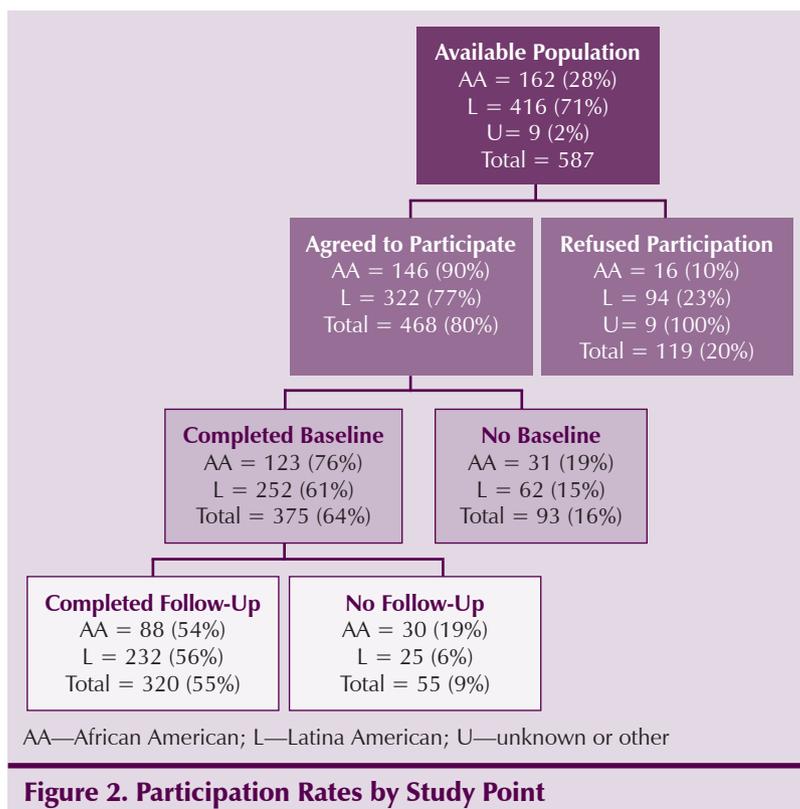


Figure 2. Participation Rates by Study Point

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 Latina Americans 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 Latina Americans 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.

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 Latina Americans (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

Table 1. Participant Demographic Characteristics

Characteristic	Total Sample (N = 320)		African American (N = 88)		Latina American (N = 232)		t/ χ^2
	\bar{X}	SD	\bar{X}	SD	\bar{X}	SD	
Age (years)	54.3	11.9	57.3	14.4	53.2	10.6	2.5*
Characteristic	n	%	n	%	n	%	t/ χ^2
Birth country							130.7**
United States	143	45	85	97	58	25	
Other	164	51	2	3	162	70	
No response	13	4	1	1	12	5	
Relationship status							8.3*
Partnered	171	53	37	42	134	58	
Unpartnered	140	44	51	58	89	38	
No response	9	3	–	–	9	4	
Education							50**
Less than high school	108	34	4	5	104	45	
High school or more	201	63	84	96	117	50	
No response	11	3	–	–	11	5	
Income (\$)							14.3*
Less than 25,000	149	47	27	31	122	53	
25,000–44,999	70	22	26	30	44	19	
45,000–75,000	40	13	16	18	24	10	
More than 75,000	51	16	18	21	33	14	
No response	10	3	1	1	9	4	
Occupation							26.5**
Homemaker	111	35	16	18	95	41	
Service	44	14	10	11	34	15	
Operator	12	4	3	3	9	4	
Technical	52	16	17	19	35	15	
Professional	72	23	31	35	41	18	
Other	20	6	11	13	9	4	
No response	9	3	–	–	9	4	

* $p < 0.05$; ** $p < 0.01$

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

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 BCSs were recruited from several sites to maximize recruitment. Another strategy outlined by the CRMRD is multilevel invitations to participation—first a mail-

Table 2. Participant Disease Characteristics

Characteristic	Total Sample (N = 320)		African American (N = 88)		Latina American (N = 232)	
	n	%	n	%	n	%
Stage						
0	17	5	6	7	11	5
I	119	37	34	39	85	37
II	126	39	32	36	94	41
III	52	16	14	16	38	16
No response	6	2	2	2	4	2
How lump was detected						
Medical examination	140	44	45	51	95	41
Breast self-examination	170	53	42	48	128	55
No response	10	3	1	1	9	4
Surgery^a						
Lumpectomy	190	59	63	72	127	57
Mastectomy	120	38	29	33	91	41
Mastectomy plus immediate reconstruction	39	12	14	16	25	11
Other treatment^a						
Chemotherapy	213	67	51	58	162	70
Radiation	222	69	59	67	163	70
Hormone therapy	207	65	53	60	154	66
Other medical conditions^a						
Hypertension	117	37	43	47	74	39
Heart disease	12	4	4	6	8	3
Diabetes	62	19	17	18	45	19
Arthritis	118	37	42	56	76	33
Osteoporosis	44	14	7	9	37	16
Psychological difficulties	92	29	13	15	79	34

^a Participants selected all that applied.

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

ing, 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 BCSs. In addition, CRAs were available during flexible hours, including mornings and late evenings.

Staff preparedness was enhanced and accomplished by preassignment 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

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 appropriate 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 primarily 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 participate, 16% of the BCSs were classified as nonresponders, and 9% of the responders were incomplete-responders (i.e., did not return follow-up survey). In addition, the proportion of African Americans in the study is of potential 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% African American and 61% Latina American), and retention (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 minority 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 behavioral 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 overarching 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 minorities 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 implement 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 Alejandro Fernandez, BA, for his contributions to the data management and analyses.

Kimlin Ashing-Giwa, PhD, is a professor at the Beckman Research Institute and a founding director of the Center of Community Alliance for Research and Education in the Department of Population Sciences, and Monica Rosales, PhD, is a research 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). Ashing-Giwa can be reached at kashing@coh.org, with copy to editor at ONFEditor@ons.org. (Submitted September 2011. Accepted for publication January 7, 2012.)

Digital Object Identifier: 10.1188/12.ONFE434-E442

References

- Ashing-Giwa, K., Ganz, P.A., & Petersen, L. (1999). Quality of life of African-American and White long term breast carcinoma survivors. *Cancer, 85*, 418–426.
- Ashing-Giwa, K.T. (2005a). Can a culturally responsive model for research design bring us closer to addressing participation disparities? Lessons learned from cancer survivorship studies. *Ethnicity and Disease, 15*, 130–137.
- Ashing-Giwa, K.T. (2005b). The contextual model of HRQoL: A paradigm for expanding the HRQOL framework. *Quality of Life Research, 14*, 297–307. doi:10.1007/s11136-004-0729-7
- Ashing-Giwa, K.T. (2008). Enhancing physical well-being and overall quality of life among underserved Latina-American cervical cancer survivors: Feasibility study. *Journal of Cancer Survivorship, 2*, 215–223.
- Ashing-Giwa, K.T., & Lim, J. (2008). Predicting health-related quality of life: Testing the Contextual Model using structural equation modeling. *Applied Research in Quality of Life, 3*, 215–230. doi:10.1007/s11482-009-9057-y
- Ashing-Giwa, K.T., Padilla, G.V., Tejero, J.S., & Kim, J. (2004). Breast cancer survivorship in a multiethnic sample: Challenges in recruitment and measurement. *Cancer, 101*, 450–465. doi:10.1002/cncr.20370
- Ashing-Giwa, K.T., Tejero, J.S., Kim, J., Padilla, G.V., & Helleman, G. (2007). Examining predictive models of HRQOL in a population-based, multiethnic sample of women with breast carcinoma. *Quality of Life Research, 16*, 413–428. doi:10.1007/s11136-006-9138-4
- Ashing-Giwa, K.T., Tejero, J.S., Kim, J., Padilla, G.V., Kagawa-Singer, M., Tucker, M.B., & Lim, J.W. (2009). Cervical cancer survivorship in a population based sample. *Gynecologic Oncology, 112*, 358–364. doi:10.1016/j.ygyno.2008.11.002
- Baquet, C.R., Ellison, G.L., & Mishra, S.I. (2009). Analysis of Maryland cancer patient participation in National Cancer Institute-supported cancer treatment clinical trials. *Journal of Health Care for the Poor and Underserved, 20*, 120–134.
- Brown, D.R., Fouad, M.N., Basen-Engquist, K., & Tortolero-Luna, G. (2000). Recruitment and retention of minority women in cancer screening, prevention, and treatment trials. *Annals of Epidemiology, 10*(8, Suppl.), S13–S21. doi:10.1016/S1047-2797(00)00197-6
- Cella, D. (1997). *FACIT manual: Manual of the Functional Assessment of Chronic Illness Therapy (FACIT) measurement system*. Evanston, IL: Center on Outcomes, Research and Education.
- Comis, R.L., Miller, J.D., Aldigé, C.R., Krebs, L., & Stoval, E. (2003). Public attitudes toward participation in cancer clinical trials. *Journal of Clinical Oncology, 21*, 830–835. doi:10.1200/JCO.2003.02.105
- Du, H., Valenzuela, V., Diaz, P., Cella, D., & Hahn, E.A. (2008). Factors affecting enrollment in literacy studies for English- and Spanish-speaking cancer patients. *Statistics in Medicine, 27*, 4119–4131. doi:10.1002/sim.3259
- Du, W., Mood, D., Gadgeel, S., & Simon, M.S. (2009). An educational video to increase clinical trials enrollment among breast cancer patients. *Breast Cancer Research and Treatment, 117*, 339–347.
- Eakin, E.G., Bull, S.S., Riley, K., Reeves, M.M., Gutierrez, S., & McLaughlin, P. (2007). Recruitment and retention of Latinos in a primary care-based physical activity and diet trial: The Resources for Health study. *Health Education Research, 22*, 361–371. doi:10.1093/her/cyl095
- Elish, N.J., Scott, D., Royak-Schaler, R., & Higginbotham, E.J. (2009). Community-based strategies for recruiting older, African Americans into a behavioral intervention study. *Journal of the National Medical Association, 101*, 1104–1111.
- Evelyn, B., Toigo, T., Banks, D., Pohl, D., Gray, K., Robins, B., & Ernat, J. (2001). Participation of racial/ethnic groups in clinical trials and race-related labeling: A review of new molecular entities approved 1995–1999. *Journal of the National Medical Association, 93*(12, Suppl.), 18S–24S.
- Farmer, D.F., Jackson, S.A., Camacho, F., & Hall, M.A. (2007). Attitudes of African American and low socioeconomic status White women toward medical research. *Journal of Health Care for the Poor and Underserved, 18*, 85–99. doi:10.1353/hpu.2007.0008
- Ford, J.G., Howerton, M.W., Bolen, S., Gray, T.L., Lai, G.Y., Tilburt, J., . . . Bass, E.B. (2005). Knowledge and access to information on recruitment of underrepresented populations to cancer clinical trials. *Evidence Report/Technology Assessment, 122*, 1–11.
- Ford, J.G., Howerton, M.W., Lai, G.Y., Gary, T.L., Bolen, S., Gibbons, M.C., . . . Bass, E.B. (2008). Barriers to recruiting underrepresented populations to cancer clinical trials: A systematic review. *Cancer, 112*, 228–242. doi:10.1002/cncr.23157
- Galea, S., & Tracy, M. (2007). Participation rates in epidemiologic studies. *Annals of Epidemiology, 17*, 643–653.
- Giuliano, A.R., Mokuau, N., Hughes, C., Tortolero-Luna, G., Risendal, B., Ho, R.C.S., . . . McCaskill-Stevens, W.J. (2000). Participation of minorities in cancer research: The influence of structural, cultural, and linguistic factors. *Annals of Epidemiology, 10*(8, Suppl. 1), S22–S34. doi:10.1016/S1047-2797(00)00195-2
- Hahn, E.A., & Cella, D. (2003). Health outcomes assessment in vulnerable populations: Measurement challenges and recommendations. *Archives of Physical Medicine and Rehabilitation, 84*(4, Suppl. 2), S35–S42. doi:10.1053/apmr.2003.50245
- Hahn, E.A., Du, H., Garcia, S.F., Choi, S.W., Lai, J.S., Victorson, D., & Cella, D. (2010). Literacy-fair measurement of health-related quality of life will facilitate comparative effectiveness research in Spanish-speaking cancer outpatients. *Medical Care, 48*(6, Suppl.), S75–S82. doi:10.1097/MLR.0b013e3181d6f81b
- Hatchett, B.F., Holmes, K., Duran, D.A., & Davis, C. (2000). African Americans and research participation: The recruitment process. *Journal of Black Studies, 30*, 664–675. doi:10.1177/002193470003000502
- Hays, R.D., Sherbourne, C.D., & Mazel, R.M. (1993). The RAND 36-Item Health Survey 1.0. *Health Economics, 2*, 217–227. doi:10.1002/hec.4730020305
- Hays, R.D., Sherbourne, C.D., & Mazel, R.M. (1995). User's manual for the Medical Outcomes Study (MOS) Core Measures of Health-Related Quality of Life. Retrieved from http://www.rand.org/pubs/monograph_reports/MR162.html
- Hiatt, R.A., Pasick, R.J., Stewart, S., Bloom, J., Davis, P., Gardiner, P., . . . Stroud, F. (2001). Community-based cancer screening for underserved women: Design and baseline findings from the Breast and Cervical Cancer Intervention Study. *Preventive Medicine, 33*, 190–203. doi:10.1006/pmed.2001.0871
- Holmbeck, G.N. (1997). Toward terminological, conceptual, and statistical clarity in the study of mediators and moderators: Examples from the child-clinical and pediatric psychology literatures. *Journal of Consulting and Clinical Psychology, 65*, 599–610. doi:10.1037/0022-006X.65.4.599
- Institute of Medicine. (2008). *Cancer care for the whole patient: Meeting psychosocial health needs*. Washington, DC: National Academies Press.
- Institute of Medicine. (2009). Review and assessment of the National Institutes of Health's strategic research plan to reduce and ultimately eliminate health disparities. Retrieved from <http://iom.edu/Activities/SelectPops/HlthDisparResNIH.aspx>
- Levkoff, S., & Sanchez, H. (2003). Lessons learned about minority recruitment and retention from Centers on Minority Aging and Health Promotion. *Gerontologist, 43*(1), 18–26. doi:10.1093/geront/43.1.18
- MacKinnon, D.P., & Fairchild, A.J. (2009). Current directions in mediation analysis. *Current Directions in Psychological Science, 18*(1), 16. doi:10.1111/j.1467-8721.2009.01598.x
- McCorkle, R., Tang, S.T., Greenwald, H., Holcombe, G., & Lavery, M. (2006). Factors related to depressive symptoms among long-term survivors of cervical cancer. *Health Care for Women International, 27*(1), 45–58. doi:10.1080/07399330500377507
- McIlvane, J.M., Baker, T.A., Mingo, C.A., & Haley, W.E. (2008). Are behavioral interventions for arthritis effective with minorities? Addressing racial and ethnic diversity in disability and rehabilitation. *Arthritis and Rheumatism, 59*, 1512–1518. doi:10.1002/art.24117
- Mishel, M.H., Germino, B.B., Gil, K.M., Belyea, M., Laney, I.C., Stewart, J., . . . Clayton, M. (2005). Benefits from an uncertainty management intervention for African-American and Caucasian older long-term breast cancer survivors. *Psycho-Oncology, 14*, 962–978. doi:10.1002/pon.909

- Moreno-John, G., Gachie, A., Flemming, C.M., Nápoles-Springer, A., Mutran, E., Manson, S.M., & Pérez-Stable, E.J. (2004). Ethnic minority older adults participating in clinical research: Developing trust. *Journal of Aging Health, 16*(5, Suppl.), 93S–123S. doi:10.1177/0898264304268151
- National Institutes of Health. (2001). NIH policy and guidelines on the inclusion of women and minorities as subjects in clinical research. Retrieved from http://grants.nih.gov/grants/funding/women_min/guidelines_amended_10_2001.htm
- Nicholson, W.K., Brown, A.F., Gathe, J., Grumbach, K., Washington, A.E., & Pérez-Stable, E.J. (1999). Hormone replacement therapy for African American women: Missed opportunities for effective intervention. *Menopause, 6*(2), 147–155.
- Portillo, C.J., Villarruel, A., de Leon Siantz, M.L., Peragallo, N., Calvillo, E.R., & Eribes, C.M. (2001). Research agenda for Hispanics in the United States: A nursing perspective. *Nursing Outlook, 49*, 263–269. doi:10.1067/mno.2001.119691
- Powell, J.H., & Fleming, Y. (2000). Making medicines for America: The case for clinical trial diversity. *Journal of the National Medical Association, 92*, 507–514.
- Sandgren, A.K., & McCaul, K.D. (2003). Short-term effects of telephone therapy for breast cancer patients. *Health Psychology, 22*, 310–315. doi:10.1037/0278-6133.22.3.310
- Schmotzer, G.L. (2012). Barriers and facilitators to participation of minorities in clinical trials. *Ethnicity and Disease, 22*, 226–230.
- Shavers, V.L., Lynch, C.F., & Burmeister, L.F. (2002). Racial differences in factors that influence the willingness to participate in medical research studies. *Annals of Epidemiology, 12*, 248–256. doi:10.1016/S1047-2797(01)00265-4
- Stark, N., Paskett, E., Bell, R., Cooper, M.R., Walker, E., Wilson, A., & Tatum, C. (2002). Increasing participation of minorities in cancer clinical trials: Summary of the “Moving Beyond the Barriers” conference in North Carolina. *Journal of the National Medical Association, 94*, 31–39. doi:10.1016/S1047-2797(01)00265-4
- Stull, V.B., Snyder, D.C., & Demark-Wahnefried, W. (2007). Lifestyles intervention in cancer survivors: Designing programs that meet the needs of this vulnerable and growing population. *Journal of Nutrition, 137*(1, Suppl.), 243S–248S.
- Topp, R., Newman, J.L., & Jones, V.F. (2008). Including African Americans in health care research. *Western Journal of Nursing Research, 30*, 197–203. doi:10.1177/0193945907303063
- U.S. Census Bureau. (2012). USA QuickFacts. Retrieved from <http://quickfacts.census.gov/qfd/states/00000.html>
- Wendler, D., Kington, R., Madans, J., Van Wye, G., Christ-Schmidt, H., Pratt, L.A., . . . Emanuel, E. (2006). Are racial and ethnic minorities less willing to participate in health research? *PLoS Med, 3*(2), e19. doi:10.1371/journal.pmed.0030019
- Yancey, A.K., Ortega, A.N., & Kumanyika, S.K. (2006). Effective recruitment and retention of minority research participants. *Annual Review of Public Health, 27*, 1–28.