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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,