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, & Hahn, 2008; Ford et al., 2005), and cultural elements (e.g., religious and health beliefs) (Brown, Fouad, Basen-Engquist, & Tortolero-Luna, 2000; Comis, Miller, Aldige, & Hahn, 2008; Ford et al., 2005).