Evaluation of Conceptual Framework for Recruitment of African American Patients With Breast Cancer

Sue P. Heiney, PhD, RN, FAAN, Swann Arp Adams, PhD, Linda M. Wells, MA, RN, FAAN, PHR, and Hiluv Johnson, BA

Recruitment, particularly minority accrual, is the Achilles heel of research (Mills et al., 2006; U.S. Department of Health and Human Services, 2000). Accrual to national cooperative clinical trials is 5%–10% (Peppercorn, Weeks, Cook, & Joffe, 2004), and accrual to cancer control and behavior studies ranges from 14%–41% (Carlson, Speca, Patel, & Goodye, 2004; Keyzer et al., 2005; Linden et al., 2007; Margitl et al., 1999; Motzer, Moseley, & Lewis, 1997; Ott, Twiss, Walthman, Gross, & Lindsey, 2006; Richardson, Post-White, Singleton, & Justice, 1998) with few exceptions (Gil et al., 2006). African American participation in studies usually is 5% or less (Bakitas et al., 2009; Blacklock, Rhodes, Blanchard, & Gaul, 2010; Dirksen & Epstein, 2008; Powell et al., 2008). Although multiple and costly efforts have been instituted to increase accrual, researchers still are challenged to meet sample size requirements for their studies. Multiple barriers, such as patient, clinician, system, and trial design, have been cited as contributing to an inability to reach recruitment goals (Advani et al., 2003; BeLue, Taylor-Richardson, Lin, Rivera, & Grandison, 2006; Cudney, Craig, Nichols, & Weinert, 2004; Dancy, Wilbur, Talashek, Bonner, & Barnes-Boyd, 2004; Heiney et al., 2006; Lichtenberg, Brown, Jackson, & Washington, 2004; Linden et al., 2007; Sears et al., 2003). In addition, knowledge of the unethical research conducted during the U.S. Public Health Service Tuskegee Research Project syphilis study often is cited as a reason for nonparticipation by African Americans (Brandon, Isaac, & LaVeist, 2005; Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; Freimuth et al., 2001; Katz et al., 2006, 2007; McCallum, Arekere, Green, Katz, & Rivers, 2006; Shavers, Lynch, & Burmeister, 2000, 2001, 2002; Wasserman, Flannery, & Clair, 2007; White, 2005). However, Heiney, Parrish, Hazlett, Wells, and Johnson (2008) found that 68% of African American participants felt that they received the same quality of health care as other ethnic groups and only 38% were aware of the Tuskegee Research Project. In addition, policies emanating from the Health Insurance Portability and Accountability Act (HIPAA) have hampered recruitment (Bowen et al., 2007; Rusnak, 2003).

Factors have been identified that influence minority participation in cancer research, particularly women and African American populations (Brown, Fouad, Basen-Engquist, & Tortolero-Luna, 2000; Outlaw, Bourjolly, & Barg, 2000; Shaya, Gbarayor, Yang, Agyeman-Duah, & Saunders, 2007). Most of the literature focuses on lessons learned in recruitment for specific cancer control...