Perceptions of Support Among Older African American Cancer Survivors

Jill B. Hamilton, PhD, RN, Charles E. Moore, MD, Barbara D. Powe, PhD, RN, Mansi Agarwal, MPH, and Pamela Martin, PhD

Patients diagnosed with cancer are living longer. An estimated 11 million cancer survivors are alive in the United States today, and the five-year survival rate for some cancers is as high as 90% (American Cancer Society [ACS], 2010). Cancer survival rates for African Americans also are improving. Since the 1960s, the overall five-year survival rate for African Americans has more than doubled, from 27% to 58% (ACS, 2010). Although these figures show that survival disparities are diminishing, African Americans continue to suffer disproportionately from cancer as they continue to have more advanced disease (ACS, 2010), less access to timely treatments and quality care (Shavers & Brown, 2002), and more comorbidities (Bryant & Cerfolio, 2008).

This cancer burden is compounded by a social environment in which social stigma and fatalistic attitudes toward cancer are prevalent (Phillips, Cohen, & Moses, 1999; Powe & Finnie, 2003) and in which healthcare institutions discriminate against the poor and minorities (Burgess, Ding, Hargreaves, van Ryn, & Phelan, 2008; Hausmann, Jeong, Bost, & Ibrahim, 2008). When a diagnosis of cancer is confirmed, African Americans experience a myriad of supportive and unsupportive responses from family and friends (Grange, Matsuyama, Ingram, Lyckholm, & Smith, 2008). These responses are critical because they may affect whether survivors are adherent to recommended treatment and affect their overall quality of life during the cancer experience. However, researchers have not fully explored older African American cancer survivors’ perceptions of their social support and the implications of these needs on their survivorship experiences.

The purpose of this study was to explore the social support needs from the perspective of older African Americans diagnosed with and treated for cancer. African Americans’ involvement in mutual aid systems of giving and receiving support makes them an exemplar population for studying supportive relationships (Hamilton & Sandelowski, 2004). Their unique experiences in collectively pooling resources to meet their needs, coupled with their experiences of having the highest overall incidence and lowest survival rates of any racial or ethnic group (ACS, 2010) provide the opportunity to analyze the complexity of supportive social relationships among this population.

Purpose/Objectives: To explore the perceived social support needs among older adult African American cancer survivors.

Research Approach: Qualitative design using grounded theory techniques.

Setting: Outpatient oncology clinics in the southeastern United States.

Participants: Focus groups with 22 older adult African American cancer survivors.

Methodologic Approach: Purposeful sampling technique was used to identify focus group participants. In-depth interviews were conducted and participants were interviewed until information redundancy was achieved.

Main Research Variables: Social support needs of older adult African American patients with cancer.

Findings: Social support was influenced by (a) symptoms and treatment side effects, (b) perceptions of stigma and fears expressed by family and friends, (c) cultural beliefs about cancer, and (d) desires to lessen any burden or disruption to the lives of family and friends. Survivors navigated within and outside of their networks to get their social support needs met. In some instances, survivors socially withdrew from traditional sources of support for fear of being ostracized. Survivors also described feeling hurt, alone, and socially isolated when completely abandoned by friends.

Conclusions: The support from family, friends, and fellow church members is important to positive outcomes among older African American cancer survivors. However, misconceptions, fears, and negative cultural beliefs persist within the African American community and negatively influence the social support available to this population.

Interpretation: Early identification of the factors that influence social support can facilitate strategies to improve outcomes and decrease health disparities among this population.