



In Their Own Words: the lived experience of African American breast cancer survivors

Center for Health Policy and Ethics

African American women have a higher breast cancer mortality rate at every age and a lower survival rate than any other racial or ethnic group in the United States. Efforts undertaken to discern the cause of cancer disparities in this population have focused on a variety of factors such as individual factors, social and economic inequalities, and the physical environment. Studies on interventions and care delivered to vulnerable and under-represented minorities have largely focused on the screening and early detection phase of cancer (Millon-Underwood et al 2008, p. 238). There is little information about the lived experiences of African American women regarding the treatment component of the acute stage of breast cancer.

Partnering

Preliminary discussions between the Center for Health Policy and Ethics (CHPE) faculty and African American women community partners, some of whom are breast cancer survivors, indicated that the significant distress at the time of diagnosis may be universal for all women with breast cancer but the experience may differ from that point on as vital treatment decisions are made. CHPE partnered with My Sister's Keeper Breast Cancer Support Group for African American Women. A pilot study was conducted to explore the lived experience of African American women in Omaha, Nebraska who are breast cancer survivors relative to received information about treatment options, symptom management, and invitation to participate in clinical trials.

Millon-Underwood S, Phillips J, Powe BD. Eliminating cancer-related disparities: How nurses can respond to the challenge. *Semin Oncol Nurs.* 2008; 24(4):279-291.



African American Women with breast cancer face many obstacles in the course of their diagnosis and treatment. This study gives voice to what would be helpful for patients and health care providers during this difficult time.

Focus groups were determined as the most effective way to capture the women's authentic experiences. Twenty-one women participated in focus groups in the Fall of 2010 and Spring of 2011. The demographic data for the groups is as follows:

- 21 participants in 4 focus groups held in November, 2010 and March, 2011
- Age range: 31 – 68 with a mean age of 53.9
- Education level: Ranged from "Did not graduate from high school" to Masters degrees; 38% had an associate degree or some college
- More than half worked outside the home (52%)
- More than half were married (52%) with an average of 23.5 years of marriage
- 90% had health insurance when undergoing treatment
- Survivorship ranged from less than a year to more than 5 years but three women had a recurrence
- Most cancer was at Stage IIa or IIb (38%)
- Almost all had surgery (90%), 76% had chemotherapy and 66% had radiation therapy.

Preliminary Findings

At the conclusion of the focus groups, themes were identified in the transcribed texts. Themes that emerged were grouped into *Things Patients Should Know* and *Things Health Care Providers Should Know*. A need expressed across all the groups was a means to record information relevant to diagnosis and treatment. With the input of women from each of the focus groups, a small folding card was designed for this purpose. The women felt it would be helpful not only to them but also to their family members as a way of retaining this information. This group also confirmed that the themes identified captured the dialogue from each focus group. What came next was a very energetic discussion as to how "get the word out"! Proposed follow up activities include an education grant to carry forward ideas developed by volunteers from the Focus Groups to determine key issues in generating culturally appropriate educational materials to raise awareness about breast health issues including:

- Develop culturally appropriate educational resources to assist African American women before during and after diagnosis and treatment.
- Distribute educational resources via outlets within the North Omaha community as identified with consultants.
- Develop and distribute educational materials helpful to healthcare providers treating African American women with breast cancer.

Ignatian Values Reflection

While CHPE embarked on this study mindful of Ignatian Values, the faith-filled women of the focus groups seemed to carry these values into all aspects of the discussion and future planning. Particularly, these women are *Women for and with Others* seeking to become *Agents for Change* with a heightened *Unity of Mind and Heart*. Within this setting, the four Creighton values represented on the inaugural cross: academic excellence, unwavering faith, compassionate patient care, and service to others were readily incorporated into the study.

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