Disparities in Breast Cancer and the Role of Patient Navigator Programs

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Despite advances in screening techniques and early detection modalities, breast cancer remains the most common malignancy affecting women in the United States. Therapeutic treatment options for breast malignancies vary in nature and are complex, with outcomes dependent on a plethora of variables. Lack of health insurance, racial disparities, limited access to medical care, socioeconomic status, underuse of available therapies, and inadequate follow-up are noted barriers to the diagnosis and treatment of patients with breast cancer. Patient navigation programs have shown a benefit in assisting these patients through screening, diagnosis, and treatment phases. This literature review will attempt to outline the obstacles associated with timely diagnosis and management of complex breast malignancies while highlighting the impact on professional practice.

Breast cancer persists as the most common malignancy in American women. In 2011, an estimated 230,480 women were diagnosed with invasive breast cancer (American Cancer Society, 2012; DeSantis, Siegel, Bandi, & Jemal, 2011). Various multifactorial causes for disparities in breast cancer care remain prevalent. The most noted barriers to attaining appropriate diagnosis and treatment for breast malignancies include African American and Hispanic ethnicity, low socioeconomic status, access to health insurance, a lack of continuity in medical care, communication challenges, education level, decreased social support, family health priorities, healthcare practices, and cultural beliefs (Ferrante, Chen, & Kim, 2007). The elimination of those noted barriers would significantly reduce the abundance of healthcare disparities for patients diagnosed with breast cancer. This article reviews the current nursing literature on disparities in breast cancer care and the role of the patient navigator program, while providing insight on how health disparities and patient navigation impact professional practice.

Literature Review

The author conducted a thorough review of the literature using the PubMed and CINAHL® databases with the following keywords: health disparities, breast cancer care, patient navigator programs, ethnicity, and socioeconomic status. To understand how barriers affect the diagnosis and treatment of breast cancer, having knowledge of the framework behind breast cancer care is imperative. The National Comprehensive Cancer Network (NCCN) offers clinical practice guidelines based on disease status. Therapeutic treatment options for breast cancer vary in nature and are complex. Guidelines for initial evaluation, treatment recommendations, and follow-up have been established based on the results of numerous clinical trials that have assessed the efficacy of those recommendations (NCCN, 2012). In addition, staging, pathology assessment, treatment approaches, and adequate follow-up must be performed in accordance with NCCN guidelines to achieve optimal clinical outcomes. As researchers continue to debate the most noted barriers to breast cancer diagnosis and treatment, the American Society of Clinical Oncology’s (ASCO’s) Health Disparities Advisory Group issued a policy identifying low income, lack of insurance, and access to care as the key components in disparities of breast cancer (Dunn, Agures-Collins, Browne, Lubet, & Johnson, 2010).

Lack of Health Insurance and Access to Screening

Despite recommendations for annual breast screening mammography for women aged 40 years and older, lack of adherence...
has been reported (McAlearney, Reeves, Tatum, & Paskett, 2005). Perceptions about health insurance coverage and cost are leading barriers to undergoing screening mammography; patients report the cost of mammography as an obstacle to proceeding with the examination (McAlearney et al., 2005).

After investigating health insurance coverage for the cost of a mammography, McAlearney et al. (2005) recognized that 40% of the sample (N = 897) had an inadequate understanding of the coverage provided by their insurance carrier. In addition, those perceptions of insurance coverage were divided into three categories: appropriate, underestimatated, or overestimated. McAlearney et al. (2005) concluded that misconceptions among coverage and cost were ubiquitous in study participants. That evidence supports educating women about appropriate screening costs and coverage.

Patients in the United States who are not covered with private health insurance often do not follow recommended screening guidelines and tend to experience gaps in access to medical care (McAlearney et al., 2005). Uninsured patients with breast cancer often present with a higher stage or more aggressive tumor at diagnosis (Halpern et al., 2008). Advanced stage at diagnosis also is common in patients with breast cancer who do not have routine screening, despite having Medicaid benefits (McAlearney et al., 2005). Social and cultural factors, which may limit access to screening and early detection modalities even for those with adequate health coverage, continue to be addressed.

ASCO has embarked on an extensive campaign to enhance awareness and improve access to cancer care. Lack of adequate health insurance was determined to be a significant barrier for patients to have access to cancer care. In 2011, 25% of Americans aged 19–64 years were uninsured (Collins, Robertson, Garber, & Doty, 2012). That statistic is alarming, as uninsured patients are less likely to seek preventive care and often delay pursuing medical attention when a need arises (Moy et al., 2011). Lack of health insurance also has shown a negative impact on cancer outcomes, and ASCO has focused its efforts on encouraging healthcare reform to include healthcare coverage for all Americans (Goss et al., 2009). In 2010, President Obama enacted the Patient Protection and Affordable Care Act, allowing legislators an opportunity to address disparities within cancer care. Although the law and its amendments will not fully eliminate healthcare disparities, a foundation has been laid to assist lawmakers in making new policies that affect healthcare reform (Moy et al., 2011).

**Racial Disparities**

Research in breast cancer examining race and ethnic variations in the United States has focused on incidence, stage at diagnosis, and cancer outcomes (Lantz et al., 2006). Age-adjusted mortality rates for African American women in the United States are 36.4 deaths per 100,000 versus 28.3 deaths per 100,000 in Caucasian women (Carey et al., 2006). That finding reflects the influence of access to care, use of early screening modalities, and adherence to recommended treatment regimens on prognosis (Lantz et al., 2006).

The reasons for poor outcomes in African American women remain unclear; however, a link identifying negative prognostic indicators within African Americans has been described. When examining subtypes of breast malignancies, Carey et al. (2006) found premenopausal women of African American descent presented with tumors that were negative for hormone receptor proteins, indicating a more aggressive tumor morphology. African American women are diagnosed later and have decreased survival compared to their Caucasian counterparts (Hawley, Fagerlin, Janz, & Katz, 2008). Racial differences may result in inadequate knowledge of breast cancer screening and treatment options. Differences in communication patterns and varying educational levels continue to impact screening patterns and breast health behaviors in African American women. Although many factors may contribute to poor prognosis, African American women demonstrate reduced survival outcomes when compared to women of other ethnicities (Hawley et al., 2008).

Inadequate follow-up after the diagnosis and initiation of adjuvant therapies is an additional barrier in the management of patients with breast cancer (Kim, Ferrante, Won, & Hameed, 2008). African American women have a longer delay between breast cancer diagnosis and initiation of treatment (Haideri & Moormeier, 2011; Koh, Nelson, & Cook, 2011). Data have suggested that African American women are substantially less compliant with postoperative adjuvant treatment recommendations than other ethnic groups (Banning, 2011). Additional investigation revealed a higher level of mistrust in healthcare professionals within the African American community (Kim et al., 2008).

**Socioeconomic Status**

An additional variable that is a known barrier among patients with breast cancer is socioeconomic status (Ademuyiwa et al., 2011; McKenzie & Jeffreys, 2009). Low income status often is not defined in the literature because that information is not collected or reported in patient medical records (Clegg et al., 2008). Income status and outcomes in minority women with breast cancer are important factors when assessing length of time from suspicious mammography to diagnosis and treatment (Ell et al., 2002). Lead-time bias, which results from delay in diagnosis, may result in more advanced stages at presentation. That may be attributed to poor socioeconomic status and lack of access to screening modalities.

**Although Caucasian women have a higher rate of breast cancer than African Americans, women with lower socioeconomic status are more likely to have poor outcomes of their disease, regardless of race or ethnicity.**

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**Exploration on the Go**

When patients are diagnosed with breast cancer, their adherence to treatment is adversely affected by their socioeconomic status. The pilot Screening Adherence Follow-Up Program (SAFe) (Ell et al., 2002) was designed and implemented to reduce known barriers to breast cancer care for minority women of lower socioeconomic status with an abnormal mammography finding. The study validated that women who were receiving SAFe services in Los Angeles, CA, were five times more likely to remain adherent to their follow-up and treatment than patients not enrolled in the program (Ell et al., 2002). The study has shown a positive increase in adequate follow-up and adherence to treatment in this higher-risk population.

Although Caucasian women have a higher rate of breast cancer than African Americans, women with lower socioeconomic status are more likely to have poor outcomes of their disease, regardless of race or ethnicity (Gordon; 2003; Vona-Davis & Rose, 2009). That notion prompted an investigation of race, socioeconomic status, and survival in patients with breast cancer. Gordon (2003) found African American women with breast cancer were younger in age, had larger tumor sizes, and had lower socioeconomic status. Race may impact overall survival, but not necessarily disease-free survival. In addition, socioeconomic status has played a key role in both disease-free and overall survival (Gordon, 2003). African American and Hispanic women with stage 0–III breast cancer demonstrated similar adverse outcomes compared to a Caucasian cohort (Lantz et al., 2006).

Underuse of Available Therapies

An important barrier within breast cancer care is underuse of available treatment. Despite recognition that adjuvant therapy for early-stage malignancies of the breast has shown significant benefit to disease-free and overall survival, those therapies remain underused (Bickell & Cohen, 2008). Racial disparities also exist among Caucasian and African American women in relation to treatment because African American women are less likely to receive radiotherapy, chemotherapy, and hormonal therapy and often experience an increased length of time for initiation of treatment (Bickell & Cohen, 2008). Those authors described a model of underuse identifying factors impacting breast cancer treatment within the community and healthcare systems. Inadequate transportation, unsafe home environment, and lack of adequate social support limit access to healthcare providers. Financial constraints, including inadequate health insurance and low income, create barriers to breast cancer treatment. Factors within the healthcare system, including inadequate understanding of different cultures, linguistic differences, and predisposed beliefs, also negatively impact patient education. In addition, miscommunication in regard to patient follow-up creates barriers to breast cancer care (Bickell & Cohen, 2008).

Lack of social assistance, supportive programs, and travel aid within the community may adversely impact breast cancer outcomes. ASCO has recommended that medical schools should enhance the education of students, as well as the continuing education of practicing physicians, to improve recognition of healthcare disparities among all oncology healthcare providers, including nurses. Curriculum content should include measures to improve cultural and linguistic competence and the appropriate use of medical interpretation services. Several institutions have embraced the notion of those medical education efforts, but continuing collaboration is advisable to ensure coordinated training on healthcare disparities (Goss et al., 2009).

In addition, proper check-and-balance systems to monitor and encourage patient follow-up positively impact breast cancer care. Patients often disclose financial and insurance coverage status as factors that affect their ability to receive recommended treatment. The knowledge and beliefs of physicians and advanced practice providers, as well as payment incentives, have been reported to impede breast cancer therapies (Goss et al., 2009).

Documented barriers causing underuse of available therapies are further described as patient, physician, and system barriers (Bickell & Cohen, 2008) (see Figure 1). As a result of those barriers, patients may be lost to follow-up and life-sustaining treatments may not be administered.

Fears and misconceptions often deter patients from proceeding with adjuvant therapies, despite recommendations. Women who decline recommended adjuvant treatments may not be aware of their benefit to survival.

Patient Navigation in Breast Cancer Care

With the identification of disparities within the ethnic and minority breast cancer population, patient navigation programs were initiated in the early 1990s, beginning at Harlem Hospital (Ferrante et al., 2007). Patient navigation is a process in which designated hospital personnel assist patients through the complexities of the healthcare continuum from diagnosis to survivorship. Patient navigators have a unique role in patient

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<td>Fear of side effects related to adjuvant therapy</td>
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<td>Fear related to risk versus benefit</td>
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<th>Physician Barriers</th>
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<td>Adjuvant therapy is not recommended by the treating surgeon.</td>
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<td>Advanced patient age and comorbidities influence physicians’ beliefs toward adjuvant therapy.</td>
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<th>System Barriers</th>
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<td>Lack of referral to medical oncology</td>
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<td>Loss to follow-up</td>
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FIGURE 1. Barriers Causing Underuse of Breast Cancer Therapies

Note. Based on information from Bickell & Cohen, 2008.
care and are crucial in building working relationships between the patient and members of the cancer care team (Phillips et al., 2011; Robinson-White, Conroy, Slavish, & Rosenzweig, 2010). In addition to establishing trusting relationships, the patient navigator also is responsible for problem solving, critical thinking, and supporting patients as they circumnavigate the healthcare system from diagnosis to surveillance. An itemized description of the role of a patient navigator is shown in Figure 2. Patient navigation is believed to have been a critical determinant of improved outcomes in Harlem Hospital patients; improvements in outcomes were noted by an increase in screening and earlier stage at diagnosis (Ferrante et al., 2007; Weber, Mascarenhas, Bellin, Raab, & Wong, 2012).

Patient navigation was created as an intervention to decrease barriers among women diagnosed with breast cancer (Vargas, Ryan, Jackson, Rodriguez, & Freeman, 2008). Programs focus on minority and underserved women with breast cancer following suspicious mammography, as minority women often delay seeking further evaluation and treatment because of communication barriers, financial concerns, cultural factors, health beliefs, and mistrust of their medical team (Ferrante et al., 2007). Implementation of a patient navigator program for minority patients with a culturally matched navigator who assists them through the hospital experience decreases anxiety, improves timeliness of diagnosis, and hastens the start of treatment (Ferrante et al., 2007).

Korber, Padula, Gray, and Powell (2011) assessed programs designed to match patients with nurses who spoke their native tongue and understood their cultural variances. Tailoring cancer care by using a patient navigator when appropriate may increase the rate of treatment completion. In that study, nurse navigators provided education, symptom management, referrals to community resources and financial assistance programs, and collaboration among the healthcare team to improve completion of breast cancer therapy (Korber et al., 2011). Language barriers between the physician and patient, despite interpreter services, contributed to inadequate follow-up care and were documented obstacles within the patient navigator program (Korber et al., 2011).

The Moffitt Cancer Center is evaluating the efficacy of its own patient navigator programs in the breast and colorectal cancer divisions. That effort attempts to minimize the delay between screening and diagnosis of an abnormality (Wells et al., 2011). Given that minority and underserved patients often present with more advanced stages at cancer diagnosis, those programs may benefit patients by decreasing delays of necessary screening and diminishing interruptions to further evaluation and treatment. By focusing on detecting and eradicating barriers within cancer care services, the number of patients who obtain recommended therapies is expected to improve (Wells et al., 2011). The three-phase implementation of the patient navigation program included developing a culturally appealing navigation program; performing a randomized, controlled trial evaluating the efficacy of the program; and summarizing findings. A large focus was developing educational resources that were appropriate to patients’ culture, literacy, and language preference. The results of that study are pending.

In 2005, federal policymakers demonstrated their support for the Patient Navigator Outreach and Chronic Disease Prevention Act by further amending the Public Health Service Act. As a result, a public law for government funding toward developing patient navigation programs through 2010 was implemented (Urrea, 2009). A total of $25 million in grant funding over a five-year span has been awarded to various healthcare organizations to develop and study the impact of patient navigation within their institutions (Urrea, 2009). For more information about money awarded for patient navigation programs, see Urrea (2009).

Conclusions and Implications for Nursing

Despite early development of patient navigation programs and services, the data measuring the impact of navigator programs and outcomes related to breast cancer remain limited. As patient navigation programs continue to expand, research of the impact on clinical outcomes is needed because few studies have examined the value of those programs. Future randomized, controlled trials may reveal the role of patient navigation in the survival of patients being diagnosed and treated for breast cancer. Additional studies focusing on decreasing barriers during breast cancer care are needed.

Understanding the effects of disparities on breast cancer care is a responsibility of the healthcare provider. Although adjuvant therapy for early-stage breast cancer has shown significant benefit in both disease-free and overall survival rates, underuse of those therapies is still evident and catastrophic. Disparities among women with breast cancer continue to represent a barrier to care. Data suggest that lower socioeconomic status and ethnicity may play a role in decreased access to breast cancer care. In addition, survival has been negatively impacted in that patient population, despite advancements in early screening and improved treatment modalities. Patient navigation programs have shown benefit in assisting patients
with breast cancer through the screening, diagnosis, and treatment phases. However, additional studies are needed to examine their impact on outcomes for patients who lack access to standard breast cancer care.

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References


