Social Disconnection in African American Women With Breast Cancer

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The American Cancer Society ([ACS], 2013a, 2013b) predicted that 27,060 new cases of breast cancer would be diagnosed in African American women in 2013, compared to an estimated 232,340 new cases among all races. Breast cancer is the most common cancer diagnosis among African American women and has a higher mortality rate in African American women than in other races, with 6,080 estimated deaths compared to 39,620 in all races (ACS, 2013a, 2013b). Biologic and genetic factors, stress, and negative social environments may decrease survival rates (Berz et al., 2009; Vona-Davis & Rose, 2009). Minimal theory has been developed to provide a framework for examining outcomes in African American women with breast cancer. Even fewer theory-based interventions exist to improve social outcomes for African American women with breast cancer. Before building theory, however, concepts must be defined in relation to how African American women experience breast cancer.

The purpose of the current article is to define social disconnection, discuss distinctions from related concepts, describe the antecedents and consequences of social disconnection, and provide direction for future research. This article focuses on African American women diagnosed with breast cancer, but the author recognizes that social disconnection may occur in any patient with cancer. The focus is on African American women with breast cancer because literature suggests that health disparities and poor survival outcomes exist, and those negative aspects may influence social disconnection (Berz et al., 2009; Eisenberger & Cole, 2012). African American women traditionally rely on extended family, faith-based organizations, and coworkers for assistance with life problems. The past reliance on large social support networks may be why social disconnection is particularly distressing to African American women (Shelby et al., 2008).

The current article follows an unorthodox approach to concept definition and analysis. The article does not

Purpose/Objectives: To identify antecedents and consequences of social disconnection in African American women diagnosed with breast cancer as described in the extant literature.

Data Sources: Literature review using broad exploration of a personal database and informal exploration of databases such as MEDLINE®, as well as clinical experience.

Data Synthesis: A formal definition, antecedents, and consequences of social disconnection were drawn from a review of the literature.

Conclusions: Antecedents included personal responses to a breast cancer diagnosis and cultural influences. Consequences included decreased well-being, partner abandonment, and decreased health.

Implications for Nursing: Areas for future research include using measurement tools for assessment, as well as creating categories for the trajectory of social disconnection and determining its severity and nature. Nurses should be alert to the possibility of social disconnection in patients with cancer. Nurses can assist the patient in talking to his or her family and friends about the cancer diagnosis and treatment.

Key Words: African American, breast cancer, social disconnection, women

strictly follow the steps laid out by Walker and Avant (1994) for concept analysis. It omits cases and, instead, borrows from concept synthesis and uses clinical experience. The work began in 2002, when the author attended a workshop that focused on designing and implementing nursing interventions. An experiential component of the workshop was to conceive a nursing problem and create an intervention to address it. Using inductive reasoning based on 25 years of clinical practice with patients with cancer living in rural communities, disruption in relationships following a cancer diagnosis was identified as a problem. The problem was derived from counseling sessions with patients and supervision of psychosocial staff caring for patients and families. Thinking about their social relationships,

patients said, "You get to know who your real friends are." Those patients described feeling hurt, isolated, lonely, and invisible. Patients reported that financial burdens and lack of transportation limited their access to health care and emotional support.

An informal literature search of existing social and communication theories was undertaken to find a theory that matched the idea of disruption in relationships after a cancer diagnosis. Miller (1976), a feminist theorist, believed that women's emotional growth and development occurred through significant connections with other women. The problem conceived by the author of the current article included the entire social network, so the term "social" was added to the theory. At that time, the concept was not found in the literature. The author reviewed studies about women's experiences with breast cancer, particularly participant descriptions of relationship difficulties (Grange, Matsuyama, Ingram, Lyckholm, & Smith, 2008; Hamilton, Moore, Powe, Agarwal, & Martin, 2010; Lackey, Gates, & Brown, 2001; Wilmoth & Sanders, 2001). From the review, the term "social disconnection" was identified and loosely defined as being cut off from individuals in highly valued relationships. The research did not name the description of social disconnection as such. However, the concept was retained because it was reflective of Miller's theory of connection and relationships being disrupted by the cancer experience. For the current article, literature was reviewed using the terms *breast cancer*, *African American*, *social disconnection*, *social networks*, and *social support*.

Disconnection and social disconnection have been referenced relatively recently in research. Disconnection was used in research on depressed adolescents to describe dimensions of loneliness and types of relationships (Hetherington & Stoppard, 2002; Joiner, Lewinsohn, & Seeley, 2002). Roxborough et al. (2012) discussed social disconnection in relation to bullying and social hopelessness in suicidal children and adolescents, and that study developed the Perfectionism Social Disconnection Model. Muhajarine and Vu (2009) studied disconnected neighborhoods and how those settings contributed to low birth weight in infants. Walker (2004) used the term in developing her relational and cultural theory that discussed how race-based disconnection could interfere with empowerment in Caucasian and African American women. More recently, researchers have examined physiology and disconnection (Eisenberger & Cole, 2012) and neurobiologic outcomes based on a lack of bonding with others (Cacioppo & Cacioppo, 2012; Cacioppo & Hawkley, 2009; Cacioppo, Hawkley, Norman, & Berntson, 2011). Although those studies addressed relationships, they did not capture the defining attributes of social disconnection in African American women with breast cancer.

Social Disconnection and Related Concepts

The constructs of social exclusion, social isolation, decathexis, and termination were identified as being related but different from social disconnection. Social exclusion is seen as a cause of social isolation. Decathexis and termination are more closely related to social disconnection.

Social exclusion is defined as a deliberate act or acts on the part of one individual or a group of individuals to omit a person from interactions or activities (Greitemeyer, Fischer, & Kastenmüller, 2012). The exclusion occurs because of bias toward a person with an inborn characteristic (e.g., race, idiosyncratic traits). Social exclusion may be coupled with bullying. Conversely, social isolation refers to the inner experience of an individual who is the recipient of being excluded (Cacioppo et al., 2011; Cacioppo & Hawkley, 2009). The person may feel lonely or hurt that he or she has been excluded from a group or activity (Way, Taylor, & Eisenberger, 2009). Social exclusion and the resulting isolation are not the same as social disconnection because they have different causes.

Decathexis is a psychodynamic concept used to describe an individual's detaching emotional energy from an object or person (Laplanche & Pontalis, 1974). The detachment may be deliberate and may occur in a divorce or as the byproduct of an event (e.g., death) (Rando, 1986). In those cases, the person withdraws emotional energy from another person as a part of grieving the loss (Laplanche & Pontalis, 1974).

Termination is used to describe the end of a therapeutic alliance or therapeutic contract in a counseling relationship. Termination of a therapeutic alliance involves agreement between the client and therapist to consciously and deliberately end the relationship and create emotional distance (Gladding, 2006). In that case, the termination is indicative of a positive conclusion to the relationship. Social disconnection differs from termination in that social disconnection does not have to be a conscious or deliberate distancing. In social disconnection, a woman diagnosed with breast cancer perceives changes in the character of a social relationship and realizes that key elements (e.g., intimacy, empathy) are missing, which is indicative of withdrawal or detachment by the partner or friend. A friend or relative becomes emotionally distant, perhaps unconsciously, and communication or interaction with a patient with breast cancer becomes less frequent. In some cases, the relationship may resume after a period of time, but in other cases, different individuals replace the lost relationship.

Defining Attributes of Social Disconnection

Social disconnection is defined in the current article as a relationship state in which an African American woman

with breast cancer perceives the presence of emotional distance and the absence of validating communications from members of her social network. The problem of social disconnection does not exclude that African American women may experience positive growth after a diagnosis of breast cancer (Russell, Von Ah, Giesler, Storniolo, & Haase, 2008; Von Ah et al., 2012).

Social disconnection is like a bridge with structural damage. An unstable bridge prevents traffic from crossing from one side to the other; social disconnection prevents elements within a relationship from functioning. Figure 1 details the antecedents and consequences to social disconnection.

Antecedents of Social Disconnection

Social disconnection is not the result of malicious intent. It occurs because of personal responses to a diagnosis of cancer and its treatment, as well as cultural influences.

Personal Responses to Cancer Diagnosis in Social Networks

Friends and family anticipate increased anxiety during discussions with patients with breast cancer and, subsequently, avoid interactions. Fears about a cancer diagnosis and death lead to anxiety about discussing cancer (Swinney & Dobal, 2011). Individuals may remember someone who died or another negative experience involving cancer (Phillips & Cohen, 2011). Lack of knowledge about how to communicate about diagnosis and treatment makes family members, friends, and community members uncomfortable and more likely to avoid discussion (Salant & Gehlert, 2008). An individual may not make an effort to communicate and avoid interaction with a patient with breast cancer,

or if communication does occur, the discussions are trivial or lack intimacy (Henderson, Gore, Davis, & Condon, 2003).

Fear of physically or emotionally hurting a person may contribute to social disconnection, and sexual intimacy issues are a more expansive problem than social disconnection. The partner of an African American woman with breast cancer may avoid initiation of sexual relations for fear of injuring the partner after surgery or hormone therapy. In turn, the woman with breast cancer may interpret that reaction as rejection or as an indication that she is less desirable after changes in her body have occurred (e.g., hair loss) (Fatone, Moadel, Foley, Fleming, & Jandorf, 2007; Lackey et al., 2001). If physical changes are not addressed, they may lead to social disconnection because avoidance of the topic can result in strain in communication. If the African American woman with breast cancer is in the early stages of a relationship when she is diagnosed with and treated for cancer, she may be hesitant to discuss body changes such as scarring, which may negatively affect the relationship (Phillips & Cohen, 2011).

Cultural Influences

Personal response to the cancer experience, whether from the patient or members of her social network, is intertwined with influences within African American culture. Three important cultural influences (i.e., cancer fatalism, breast cancer as taboo, and the strong black woman role) are antecedents to social disconnection. Cultural influences may be defined as "norms, beliefs, and practices that are socially shared" (Flynn, Betancourt, & Ormseth, 2011, p. 81) and are influenced by multiple past and current economic and social conditions (Cherlin, 1998). Although shared norms, beliefs, and practices exist within the African American community, differences based on geography, degree of acculturation with the larger society, and personal circumstances also are present. The three aforementioned cultural influences vary depending on religious affiliation, geography, and the extent to which the patient identifies with prevailing community beliefs (Russell, Monahan, Wagle, & Champion, 2007).

Fatalistic beliefs about cancer, particularly breast cancer, have abated because of many public education campaigns about the prevention of cancer, but those beliefs persist and are likely to increase disconnection (Zollinger et al., 2010). Common beliefs include that a cancer diagnosis is a death sentence and that treatment is ineffective (Gullatte, Brawley, Kinney, Powe, & Mooney, 2010; Swinney & Dobal, 2011). Fatalistic beliefs about breast cancer held by African American women and their social network may increase anxiety related to cancer. That fear may inhibit communication within social networks and increase social disconnection.

Components of Definition
- Disturbed relationship state: Close relationship has been altered
- Emotional distance: Boundary is created
- Absence of validating communication: Lack of interactions

Antecedents
- Personal responses
- Cultural influences

Consequences
- Decreased well-being
- Partner abandonment
- Decreased physical health and increased mortality

Related Terms
- Social exclusion
- Decathexis
- Termination

Figure 1. Components of Social Disconnection

Although less prevalent, breast cancer and related women's health issues remain a taboo topic in some African American communities, and a diagnosis of cancer may not be disclosed to family and friends (Lewis, Sheng, Rhodes, Jackson, & Schover, 2012; Thomas, 2004). That lack of disclosure may be because of collective memory that feeds beliefs (e.g., causes of cancer, fear, lack of knowledge, cancer as a death sentence) about breast cancer from older to younger generations (Salant & Gehlert, 2008). Many African American women do not want to acknowledge they have cancer, which is expressed as naming or claiming the cancer (Cohen, 2009; Thomas, 2004, 2006; Wilmoth & Sanders, 2001). Because of this, women may not personally know a cancer survivor or their family histories of breast cancer (Swinney & Dobal, 2011). Multiple researchers have reported examples of the desire to keep a breast cancer diagnosis a secret from family and community (Fowler, 2007; López, Eng, Randall-David, & Robinson, 2005; Thomas, 2006). The taboo surrounding breast cancer in African American communities isolates women from support and can interfere with treatment (Salant & Gehlert, 2008).

The superwoman schema, commonly called the strong black woman role (Beauboeuf-Lafontant, 2007; Hamilton-Mason, Hall, & Everett, 2009; Woods-Giscombé, 2010), has a predominant influence on African American women with breast cancer (Henderson et al., 2003; Swinney & Dobal, 2011). In spite of having cancer, the African American woman is expected to be strong and cope with stress and demands without complaint and to carry on regardless of economic, family, or personal difficulties (Ashing-Giwa et al., 2004; López et al., 2005). That viewpoint is maintained by African American women with breast cancer and their social networks (Gates, Lackey, & Brown, 2001). The African American woman with breast cancer believes that she should not burden others with her illness. Her social network may encourage her to focus on her blessings, reflected in the common phrase, "I am too blessed to be stressed" (Poindexter, 2001; Swinney & Dobal, 2011). Because of the desire to appear strong, concerns about the disease and its treatment may not be shared with social network members, which may increase social disconnection.

Consequences

Social disconnection deprives a woman of vital support from members in her social network. The withdrawal of valued relationships leaves women feeling a sense of loss and a yearning for someone to listen to them (Grange et al., 2008). Social disconnection results in loneliness, isolation, and hurt. Those feelings are derived from the realization that members of a social network do not want to talk about cancer or that they

Knowledge Translation

Social disconnection has not been previously conceptualized in African American women with breast cancer.

Nurses who assess for social disconnection have an opportunity to intervene and improve patient relationships with social circles and improve quality of life.

Nurses should consider the problem of social disconnection when assessing all patients with cancer, as it may occur in individuals from diverse cultural and ethnic backgrounds.

cannot handle the discussion (Hamilton et al., 2010; Yoo, Aviv, Levine, Ewing, & Au, 2010).

Few studies describe consequences to social disconnection. For example, researchers do not know if social disconnection causes African American women with breast cancer to grieve lost relationships, if that grief is transitory, or if they are resilient and adept at developing new relationships. Researchers also do not know whether African American women with breast cancer internalize social disconnection as negative self-appraisal, among other consequences. To generate an informed list of consequences, the author expanded, interpreted, and applied results from other relevant studies, including those in which the concept of social disconnection was not directly named or measured. Three categories of consequences recurred in the literature: decreased well-being, partner abandonment, and decreased physical health coupled with increased mortality.

Decreased Well-Being

Social disconnection may linger for years after the diagnosis and significantly hinder emotional recovery and adjustment (Wilmoth & Sanders, 2001). When social disconnection occurs, a woman's ability to cope with cancer treatment and the associated trauma is diminished (Shapiro, McCue, Heyman, Dey, & Haller, 2010). Previous researchers have found that positive, nurturing relationships promote African American women's ability to cope with a diagnosis of breast cancer and continue treatment, suggesting that becoming disconnected from relationships could have a deleterious effect on adjustment postdiagnosis (Gallia & Pines, 2009; Gates et al., 2001; Hamilton & Sandelowski, 2003; Porter et al., 2006). A recent study also demonstrated that increased social support is related to better mental health-related quality of life (Matthews, Tejeda, Johnson, Berbaum, & Manfredi, 2012).

Partner Abandonment

Partner abandonment can be a consequence of social disconnection. African American women have expressed

concerns about partner abandonment related to breast cancer and have reported actual abandonment (Sanders, Wilmoth, & Lowry, 2004; Swinney & Dobal, 2011). Many partners are unable to handle the diagnosis and do not help make treatment decisions (Lannin, Mathews, Mitchell, & Swanson, 2002). Women lacking a partner by marriage are particularly vulnerable to abandonment from their partners (Gates et al., 2001). Sanders et al. (2004) found that having strong support by a partner was crucial to positive adjustment.

Decreased Physical Health and Increased Mortality

Social disconnection, if sustained, is known to negatively affect physical health and leads to increased mortality (Berz et al., 2009; Hawkins et al., 2010; Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006). When social disconnection occurs, African American women with breast cancer are less likely to attend to health maintenance activities, including treatment. A recent study supported the assertion that relationship quality predicts better prognosis and that the quality of social relationships may have positive or negative effects on survival (Kroenke et al., 2006).

Discussion

The purpose of the current article was to identify antecedents and consequences of social disconnection in African American women diagnosed with breast cancer. Two approaches to concept development (i.e., synthesis and analysis) were used, adapted from Walker and Avant's (1994) method. Antecedents and consequences to social disconnection in African Ameri-

can women with breast cancer have been described. The three consequences (i.e., fatalistic beliefs, taboo surrounding breast cancer, and the belief that African American women must not let stress get to them) are critically important because they provide a starting point for developing interventions to address social disconnection, which could result in its prevention.

Implications for Nursing

The conceptual analysis of social disconnection and its antecedents and consequences identified major gaps in knowledge and research on the dimensions of social disconnection. The questions listed in Table 1 may be a starting point for filling those gaps. The list is not intended to be explanatory but instead provoke or spur research.

Nurses should pay close attention when African American women with breast cancer provide information about their social relationships. They should gently inquire about who has been told about the diagnosis and how family and friends reacted. That conversation can serve as a good time to explore fatalistic beliefs and the taboo surrounding cancer. Nurses should tell patients that a cancer diagnosis can be stressful to relationships and note that talking with a counselor may be helpful. Asking the patient about her life and her responsibilities may elicit descriptions of the burdens the woman is experiencing and can help the nurse figure out how to intervene, if necessary.

Conclusions

Social disconnection (i.e., being cut off or emotionally distant from social network members) may have

Table 1. Questions for Future Research of Social Disconnection in African American Women With Breast Cancer

Category	Questions
Biology	Does a critical biologic pathway exist that is altered as a consequence of disconnection that might explain recurrence or mortality?
Measurement	How do we measure social disconnection, its dimensions, and its consequences? Are there items in existing item banks that could be used to create a measure of social disconnection?
Nature	What happens if a woman is unable to reconnect because of physical circumstances or social situations? What happens if a woman does not have adequate emotional or physical energy to expend on reconnecting? What happens if critical connections are altered by circumstances such as death or communication deficits, as may be seen in dementia or stroke?
Severity	Is there a critical number of disconnections that leads to the most negative consequences? How many disconnections occur before it affects the individual? Are some disconnections more harmful than others?
Trajectory	What is the trajectory of social disconnection? Does it parallel or intersect with the trajectory from diagnosis to survival? How do patients with recurrence or terminal disease experience social disconnection? What are the indicators that connections are being re-established or strengthened?

serious social, emotional, and physical health consequences that include decreased well-being, partner abandonment, and poor prognosis following a cancer diagnosis. Because of nurses' involvement with patients, they are ideally positioned to intervene when social disconnection occurs. Patients' disclosure about their relationships with family and friends should be carefully monitored, and if disconnection is suspected, a nurse should address the issue with the patient. Researchers also can contribute to a better understanding of social disconnection by conducting research on a range of related topics, including potential biologic pathways. Interventions that work to decrease social disconnection should be developed and tested.

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