

QUALITY OF LIFE OF THE PARTNERS OF
AFRICAN AMERICAN WOMEN WITH BREAST CANCER

by

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DEDICATION

To my grandmother, who never attended school, but believed that education was the key to success.

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ABSTRACT

QUALITY OF LIFE OF THE PARTNERS OF AFRICAN AMERICAN WOMEN WITH BREAST CANCER

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George Mason University, 2013

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The high morbidity, mortality, and treatment of breast cancer in African American women may negatively impact the quality of life of the patients and their partners. This descriptive quantitative study explored the self-reported quality of life of the partners of African American women with breast cancer in a large city and suburbs of the United States' Mid-Atlantic Region. The study surveyed African American couples whose female spouse had a diagnosis of breast cancer, who were over the age of 18, and who were married or cohabiting with a male. A demographics questionnaire for the women, a demographics questionnaire for their male partners, and the Caregiver Quality of Life Index-Cancer (CQOLC) scale were used to collect the data. Descriptive statistics were computed using SPSS for couples' demographic variables. Bivariate Spearman-Rank Correlations and Kruskal-Wallis One-Way ANOVA were used to assess the relationship between sociodemographic variables and quality of life. Bivariate Spearman-Rank correlations found statistically significantly, positive correlations between the age

of the male partner and the Burden total score. Kruskal-Wallis One-Way ANOVAs comparing differences in average Burden, Disruptiveness, Positive Adaptation, and Financial Concerns partners' total scores with marital status, religion, employment status, highest level of educational attainment and African American women's stage at breast cancer diagnosis findings showed that the average male partner's CQOLC Burden total score differed significantly by employment status. Data from descriptive statistics and independent *t*-tests demonstrated not currently employed male partners having a lower mean total Burden score.

The average total male partners' caregiver quality of life score was 74.8 with a standard deviation of ± 15.55 ; the minimum possible score was 0 and the maximum possible score was 140. The findings support the need for nurses and all healthcare providers to provide ongoing communication with patients and their partners and to develop culturally sensitive, age specific education and support.

1. INTRODUCTION

According to the American Cancer Society (ACS) (2013), breast cancer is the most common cancer among African American women and one of the leading causes of death in this population. An estimated 27,060 new cases of breast cancer are expected to occur in African American women in 2013. The 5-year survival rate for breast cancer diagnosed among African American women from 2002 to 2008 was 78%, compared to 90% among White women (ACS, 2013). Although White women have a higher rate of breast cancer, African American women have a higher morbidity and mortality.

The etiology of high morbidity and mortality associated with breast cancer in African American women has been the focus of much speculation. Research studies have cited socioeconomic factors (Altpeter, Mitchell, & Pennell, 2005; Aziz, Iqbal, & Akram, 2008; Baquest & Commiskey, 2000; Fowler, Rodney, Roberts, & Broadus, 2005; Gwyn et al., 2004; Naik et al., 2003); access to health care (Bibb, 2000; Hunter, 2000; Joslyn, & West, 2000; Royak-Schaler, Chen, Zang, Vivacqua, & Bynoe, 2003); health care decisions and practices (Fowler, 2006; Gullatte, 2006; Gwyn et al., 2004; Hahn et al., 2007; Lannin et al., 1998; Newman, 2004; Ramondetta & Sills, 2004; Stolley, Sharp, Wells, Simon, & Schiffer, 2006) and body weight (Stolley et al., 2006) as possible reasons that have contributed to the African American woman's late stage of diagnosis

and high mortality. The high incidence of morbidity and mortality of breast cancer in African American women compared to other ethnicities (Gwyn et al., 2004; Hunter, 2000; Joslyn & West, 2000) results in a large number of male partners who will experience the challenges of living with and caring for a partner with this disease.

Background

While the quality of life of partners of women with breast cancer has been investigated in other racial/ethnic populations (Baider & De-Nour, 1988; Bergelt, Koch, & Petersen, 2008; Wagner, Bigatti, & Storniolo, 2005), little information on the quality of life of the partner of the African American woman with breast cancer was located in a literature review which explored the quality of life of partners of African American women with breast cancer. A search of the Psycho INFO, Pub Med, and CINAHL databases from 1975-2009 using the keywords African American, Black, breast cancer, woman, man, husband, spouse, significant other, partner, quality of life, cope, and support produced one significant article: Morgan et al. (2005).

Morgan et al. (2005) conducted a qualitative study of 12 African American couples to ascertain the couples' strategies of coping with breast cancer. Although the study provided data on the cultural experiences of couples coping with breast cancer, the investigators recommended further research to understand family dynamics and the unique coping processes within African American families.

Like other couples, African American partners experience the effects of cancer and its treatment. The disease process and treatment can negatively affect a family's quality of life (Morgan et al., 2005). Most studies that have documented couples'

experiences with breast cancer and the impact of those experiences on quality of life have utilized predominantly White samples (Bergelt et al., 2008; Brady & Helgeson, 1999; Giese-Davis, Hermanson, Koopman, Weibel, & Spiegel, 2000; Holmberg, Scott, Alexy, & Fife, 2001; Kadmon, Ganz, Rom, & Woloski-Wruble, 2008; Northouse, 1989; Ryan, 2004; Wagner et al., 2005; Wang, Crosby, Harris, & Liu, 1999; Weihs, Enright, Howe, & Simmens, 1999; Wellisch, Jamison, & Pasnau, 1978). Little information that was specific to the partners of African American women with breast cancer could be gleaned from these studies because of the small numbers of African American participants.

The challenges of recruiting African American male participants for research studies are well known (Ford, Havstad, & Davis, 2004; Jones, Steeves, & Williams, 2009; Plowden, Wendell, Vasquez, & Kimani, 2006) and will be discussed in the Review of the Literature. Previous community research (Campbell et al., 2006; Lassater, Wells, Carleton, & Elder, 1996) has shown that churches can be rich recruitment sites for African Americans. Therefore, this study prioritized community recruitment.

Purpose of the Study

The purpose of this study was to explore the level of self-reported quality of life of partners of African American women with breast cancer.

Study Significance

The woman with a diagnosis of breast cancer has multiple physical needs; intense psychological distress which may be manifested by pain, anxiety, depression; and restrictions in social and sexual functioning (Montazeri et al., 2008). Alterations in the woman's functional ability, bodily functions, appearance, employment status, family, and

social role can be challenging for the woman (Northouse et al., 2002), and for her partner in his physical, emotional, social, and functional domains (Bergelt et al., 2008). A spouse's illness can alter the couple's emotional balance, finances, division of responsibilities, and social activities (Kaye & Gracely, 1993; Oberst & James, 1988).

Male partners of breast cancer patients assume fundamental and supportive roles in patient and family care (Northouse & Peters-Golden, 1993; Wagner et al., 2005). According to Petrie, Logan, and DeGrasse (2001), partners are the most frequent providers of care and support to women with breast cancer.

The importance of spousal support for women with breast cancer has been well documented in the literature. Research conducted with 1,715 women with breast cancer (Penman et al., 1986) showed that the support provided by friends and family was not as important as the support from a spouse or significant other. Later research confirmed that breast cancer patients view their husbands or partners as the most important confidant from whom they seek support (Figueiredi, Fries, & Ingram, 2004; Maunsell, Brission, & Deschenes, 1995). Women experience a better adjustment to cancer and greater personal growth after the cancer experience (Calhoun & Tedeschi, 1998; Weiss, 2004) when their husbands or partners are perceived as supportive. In addition, emotional support from a partner has been associated with less depression, anxiety and an improved quality of life for women with breast cancer (Helgeson & Cohen, 1996).

Partner support is not just confined to the emotional aspect of the breast cancer experience but also to the necessity to provide support and care in the daily routine and Activities of- Daily- Living (ADLs) of the woman with breast cancer. This is due to the

fact that the course of breast cancer has shifted from an acute disease with a prompt outcome, such as death, to a chronic disease with long-term treatment that is often managed at home (Feldman & Broussard, 2005).

Recent studies found that managed care systems have begun to cut costs by shifting the burden of patient care from hospitals to patients' partners and families (Feldman & Broussard, 2006). Thus, partners and other family members have become a substantial part of the informal care system in the United States (Nijboer et al., 1998).

A woman's breast cancer can cause her partner to experience a spectrum of emotions related to concerns about the anticipated physical, emotional, social, and spiritual changes stimulated by the disease and its treatment. The breast cancer experience can affect the partner's physical health resulting in increased fatigue, decreased appetite, and disturbed sleep patterns (Haley, LaMonde, Han, Narramore, & Schonwetter, 2001; Teel & Press, 1999; Wellisch et al., 1978). Other research found that the emotional health of women's partners is affected and that the psychological distress for partners of women with breast cancer may actually be greater than that of the women who have breast cancer (Nijboer, Tempelaar, Triemstra, Sanderman, & van den Bos, 2001). A breast cancer diagnosis, treatment, progression and possible death of a partner can cause the other partner to experience shock, disbelief, denial, anger, guilt, depression, anxiety, uncertainty, helplessness, fear, loss of control, and isolation (Hilton, Crawford, & Tarko, 2000; Northouse et al., 2002; Zahlis & Shands, 1991). Understanding the physical and mental health outcomes of a breast cancer diagnosis is crucial to understanding the impact of the disease on the quality of life of the partner.

The term *quality of life* is a multifaceted construct that assesses overall enjoyment of life. The term includes a number of domains such as physical, mental, spiritual, social, and socioeconomic well-being (Ferrans, 1990; Wagner et al., 2005). These domains are affected when partners must adjust to role changes and problems that may result from managing responsibilities at work and home (Morse & Fife, 1998; Woloski-Wruble & Kadmon, 2002).

Yet, despite the pivotal role assumed by male partners of women with breast cancer, most attention in the health care system has been concentrated on direct patient care issues. Issues that affect partners have been neglected or ignored by health care professionals (Northouse & Peters- Golden, 1993). The disproportionately poor outcomes of African American women with breast cancer and the lack of research on the quality of life of their male partners suggest that more research is needed to explore the breast cancer experience of the partners of African American women.

Research Questions

This study was guided by the following research questions:

1. What are the demographic characteristics of African American women with breast cancer and their partners?
2. What is the level of self-reported quality of life in the partners of African American women with breast cancer?
3. Is there any relationship between the quality of life domains—disruptiveness, burden, financial concerns, and positive adaptation—of the partners of African American women with breast cancer and the following?

- a. Age
- b. Years of education
- c. Employment status
- d. Marital status
- e. Length of time with partner
- f. Stage at breast cancer diagnosis
- g. Type of surgery
- h. Faith

Conceptual Framework

The conceptual underpinnings of this study were derived from the 1999 model of response shift and quality of life by Sprangers and Schwartz. This model highlights appraisal processes and provides a testable theoretical approach to assessing change in quality of life. The theoretical model depicted in Figure 1 was used to clarify and predict changes in perceived quality of life that result from the interaction of factors. For the purposes of this study response shift was not used.

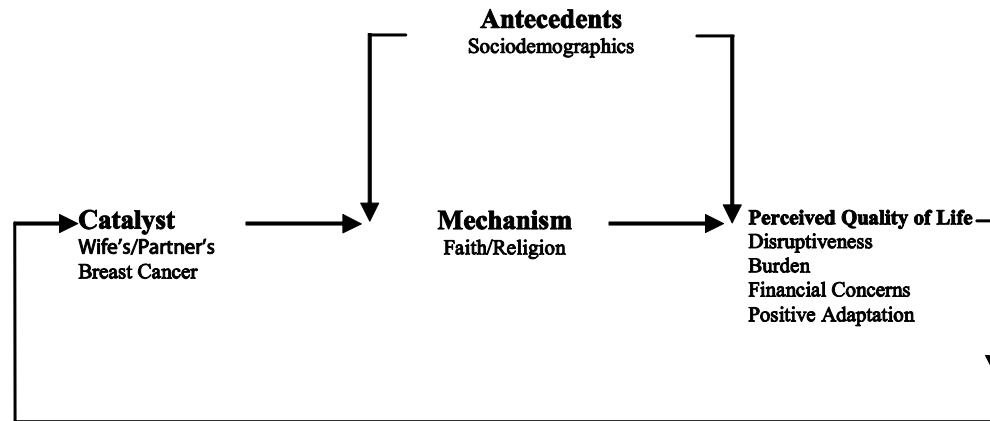


Figure 1. Theoretical model of response shift and quality of life. Adapted from “Integrating Response Shift Into Health-Related Quality of Life Research: A Theoretical Model,” by M. A. Sprangers and C. E. Schwartz, 1999, *Social Science Medicine*, 48(11), pp. 1507-1515. Used with permission.

According to Sprangers and Schwartz (1999) the factors used are defined as: (a) *catalysts*, which are health states or changes in health states, as well as other health-related events, the vicarious experience of such events, and other events that may affect or have an impact on the quality of life, such as life events; (b) *antecedents*, which are characteristics of the person and environment that may influence the likelihood and type of catalysts and mechanisms of appraisal; and (c) *mechanisms*, which include the behavioral, cognitive, or affective processes that accommodate changes in catalysts such as initiating social comparisons or reordering goals. This research utilized these conceptual definitions as the operational definitions for the study.

Definition of Terms

For the purposes of this study, the following key terms are defined.

- *Partner*: a male live-in partner, spouse, or common-law spouse (Taylor-Brown, Kilpatrick, Maunsell, & Dorval, 2000).

- *Quality of life*: a multidimensional term which includes the domains of physical, psychological, spiritual, social, and socioeconomic well-being (Ferrans, 1990; Raphael, Renwick, Brown, & Rootman, 1996; Jaracz, Gustafusson, & Hamrin, 2004).
- *African American*: a person with origins in any of the Black racial groups of Africa, such as those who indicate their race as Black, African American, Negro, or Afro American.

Summary

This chapter introduced the focus of this study as the impact of breast cancer on the quality of life of the partners of African American women, who suffer from high rates of morbidity and mortality from breast cancer. This study explored the level of self-reported quality of life of partners of African American women with breast cancer as measured by four domains: disruptiveness, burden, financial concerns, and positive adaptation; and the relationship between demographic and disease-related factors to the four domains.

The chapter also introduced the conceptual framework of the study which was guided by Sprangers and Schwartz's (1999) model of response shift and quality of life. The study results are expected to fill the void of missing literature about the impact of breast cancer on African American women's partners' quality of life.

2. REVIEW OF THE LITERATURE

This literature review is presented in the following order: search strategies, inclusion criteria, background of disease, and quality of life-related factors (disruptiveness, burden, financial concerns, positive adaptation). A summary follows the review.

Search Strategies and Inclusion Criteria

This literature review examined peer-reviewed research related to the quality of life of partners of women with breast cancer. It included published work from 1989-2009 on research which investigates quality of life. Several seminal sources prior to 1989 were also located. The literature was identified by searching four bibliographic databases: MEDLINE, Psychinfo, Pub MED, and CINAHL.

Research studies were included if they utilized any of the domains of disruptiveness, burden, financial concerns, positive adaptations, demographic, and disease-related factors to analyze the impact of the women's breast cancer experience on the partners.

Background

Disease

The incidence of breast cancer among African American women is slightly lower than it is for White women. In any given year, 95 out of 100,000 African American women are diagnosed with breast cancer, compared to 112 out of every 100,000 White

women (ACS, 2013). Despite a lower incidence, African American women have higher breast cancer mortality than White women (ACS, 2013). Additionally, African American women are more likely to be diagnosed at a more advanced stage (Ghafoor et al., 2003) and have larger, more aggressive tumors than those in White women (Newman et al., 2002).

A research study conducted in 2009 by Stead et al. at Boston University School of Medicine searched hospital records from the Boston Medical Center and focused on 415 breast cancer cases. Clinical features, patient age, weight, race/ethnicity, and pathological features including the triple-negative pattern—tumors that lack expression of the estrogen receptor, the progesterone receptor, and the HER2 gene—were reviewed. The findings revealed that the odds of having a triple negative tumor were three times higher for African American women than for White women.

This more aggressive, advanced stage of breast cancer and the morbidity and mortality associated with a breast cancer diagnosis in African American women adds credibility to the severe impact of this disease on the quality of life for both the African American woman and her partner.

Quality of Life

The negative impact of caring for a family member with cancer is well documented (Grunfeld, Coyle, & Whelan, 2004; Kurtz, Kurtz, Given, & Given, 2004; Taylor, 2003). Wellisch et al.'s (1978) research was one of the earliest studies identified that examined the spouse's reaction to breast cancer in the marital partner. Wellisch et al. (1978) studied 31 spouses of women with breast cancer surveyed post mastectomy; 29

were White, 1 was African American, and 1 was Asian. Forty percent reported sleep disorders and nightmares, 33.4% reported changes in appetite, 42% reported temporary effects on their work, and 14.3% indicated that sexuality and intimacy were bad after their partner had a mastectomy: they indicated sexuality as 21.4% somewhat bad, 57.1% indicated there was no influence at all, and 7.1% indicated it as somewhat good (Wellisch et al., 1978). The results of this study are indicative of increased levels of stress in spouses of breast cancer patients.

In 2005, Wagner et al. compared the quality of life of partners of breast cancer patients to spouses of healthy wives by using the Medical Outcomes Study SF-36 (SF-36). The sample included 79 partners of women with breast cancer and 79 partners who served as a comparison group. Partners were 93.7% Caucasian and 2.5% African American in the breast cancer group, while the comparison group was 89.7% Caucasian and 3.8% African American. Partners of the breast cancer patients scored lower on the general health, vitality, and mental health subscales than the comparison group.

Bergelt et al. (2008) conducted research on the quality of life of partners of patients with breast cancer. A total of 153 partners of breast cancer patients completed a socio-demographic form and the SF-36 questionnaire, which assessed quality of life factors such as physical functioning; role limitation; emotional, physical, and social functioning; mental health; energy; vitality; bodily pain; and perception of general health. The findings revealed that the cancer of a partner affected the partners' emotional quality of life more than physical dimensions quality of life. The burden of care has profound implications for the partner.

Disruptiveness

The partner of a breast cancer patient is faced with substantial challenges. The physical and emotional demands of breast cancer disrupt the social roles, social functioning, and functional status of the couple (Feldman & Broussard, 2006). Partners are faced with role adjustments that can culminate in problems managing responsibilities at work, home, and with other family relationships (Morse & Fife, 1998; Woloski-Wruble & Kadmon, 2002). Areas most likely to be affected are household tasks, sexual function, and marital problems.

In a descriptive research study of 24 spouses of women with breast cancer, spouses reported intense emotional reactions following their wives' diagnosis of breast cancer (Sabo, Brown, & Smith, 1986). Gotay (1984) conducted a descriptive study with 20 spouses of women with advanced breast cancer. Spouses were found to be extremely concerned about their family's future and fear of their wives' death. Northouse (1989) adds credibility to Gotay's research as she conducted interviews of 50 mastectomy patients and their husbands to evaluate the impact of the cancer experience after surgery and one month later. The common concerns of the husbands were for the survival of their wife and a return to a normal life style. A qualitative study of 67 spouses of women with breast cancer conducted at 3 and 30 days post surgery revealed the demands of the breast cancer illness that caused the greatest disruption were the physical and emotional effects the illness had on the spouse (Zahlis & Sands, 1991).

Burden of Care

Caregiving tasks for ill patients include providing transportation, shopping, homemaking services, nursing care, emotional support, and personal care (Emanuel et al., 1999; Siegel, Raveis, Houts, & Mor, 1991). Research conducted by Zahlis and Sands (1991) on the partners of 67 breast cancer patients identified seven types of caregiving demands the women's breast cancer placed on partners: reacting to the wife's illness, negotiating the illness experience, adapting the partner's lifestyle to meet the demands of the illness, being sensitive to the wife's needs, thinking about the future, attempting to minimize the effects of the illness, and feeling the impact of the illness on the relationship. Sabo (1990) found that men tend to hide behind a "tough guy" image, and employ denial to minimize their worries and cope with new duties.

The quality of the patient-partner relationship becomes increasingly important when care is provided over a long period (Northouse & Swain, 1987). Jones and Peters (1992) analyzed reports from 256 caregivers identified from a random sample of 1,079 elderly individuals. Different types of care situations appeared to have different consequences for the partner. Care situations that confined the partner to the house were more likely to have a negative effect on the partner's quality of life (Nijober, Tempelaar, Triemstra, Sanderman, & van den Bos, 1999). Situations that involved personal tasks such as feeding or washing the patient were also perceived as more burdensome than those that required nonpersonal duties such as shopping. Caring for an incapacitated individual worsens health; impairs social and family life; and increases stress, anxiety, and depression (Nijober et al., 1999).

Partners often feel unprepared to cope with both their own and their wife's emotional reactions to breast cancer (Hilton, 1994). Men use self-control to hide their feelings of sadness and fear as they struggle to focus on their wives' illness and care of their families (Hilton et al., 2000; Sabo, 1990). The Family Caregiver Model suggested that the caregiving burden of the partners of cancer patients is related to the caregiver's quality of life (Nijboer et al., 1998). This was supported by Rees, O'Boyle, and MacDonagh (2001) in a study which found that partners who are caregivers face numerous difficulties. Caregivers may feel socially isolated and find it difficult to combine the caregiving role with other family responsibilities. Research shows this causes greater psychological and emotional distress for the partners than for their wives (Nijboer et al., 2001).

Numerous studies have focused on the specific association between care burden and emotional distress in caregivers of a family member with cancer (Emanuel, Fairclough, Slutsman, & Emanuel, 2000; Kornblith, Herr, Ofman, Scher, & Holland, 1994; Nijboer et al., 1999). Northouse and Swain (1987) and Northouse (1988) conducted a series of longitudinal studies of 50 newly diagnosed breast cancer patients and their husbands. Both partners completed measures of mood, emotional distress, and psychosocial adjustment (Derogatis, 1986; Derogatis & Melisaratos, 1983). The 1987 study included measures immediately after surgery and 30 days post surgery. The study results indicated that mood and emotional distress did not differ significantly between partners, and that the moods of both partners improved significantly over time as the wife recovered. The researchers examined the relationships between demographics (age,

length of marriage), medical factors (types of surgery, number of breasts removed, extent of disease, type of adjuvant treatment), and the partners' adjustment. No significant differences were reported.

Yun et al. (2004) found that the burden of caregiving significantly affects the caregiver's quality of life. Yun et al. surveyed 738 caregivers of cancer patients who were diagnosed with lung, stomach, colon, and breast cancer. After controlling for various patient and caregiver characteristics, the researchers found that caregiver burden was associated with twice the burden and lower scores on the Caregiver Quality of Life Index-Cancer Scale (CQOLC) (Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999). Glasdam, Jenses, Madsen, and Rose (1996) measured anxiety and depression in 102 spouses of breast, uterus, ovarian, lung, skin, testicular, colorectal, and head and neck cancer patients. A significant number of spouses were identified with anxiety, depression, and physical symptoms or feelings of anger which they had not discussed prior to testing.

Grov, Dahl, Mourn, and Fossa (2005) examined anxiety, depression, and the quality of life of primary caregivers. A total of 49 caregivers of breast cancer patients and 47 caregivers of men with prostate cancer were surveyed using the Medical Outcomes Study Short Form (SF-36) (Ware & Sherbourne, 1992). Physical quality of life was higher than the norm in both genders, although the emotional quality of life was significantly lower in male caregivers. No significant level of depression was found in caregivers of either gender.

Feldmand and Broussard (2005) surveyed 71 male partners of women who were newly diagnosed with breast cancer. The researchers found that one partner's stress

affects the other. Invested partners are motivated to assist one another in coping with stressful events in order to decrease the stress of the partners, both individually and conjointly. Partners can employ negative strategies such as avoidance, or positive coping strategies such as communication in the adaptation process to the breast cancer experience. Nijboer et al. (1999) found an inverse correlation between the educational level of the caregiver and the positive impact of caregiving. In their study, those with lower levels of education were able to derive more self-esteem from caregiving.

Although the literature identifies a variety of variables that affect the burden of caregiving for cancer patients and their partners, few studies have assessed the influence of race/ethnicity on caregiving. Siefert, Williams, Dowd, Chappel-Aiken, and McCorkle (2008) studied the differences in outcomes by patient and family caregiver characteristics, including race and ethnicity. Questionnaires were used to identify sociodemographics, psychological and physical health, and burden of caregiving among 54 caregivers, 35% of whom were identified as African American or Hispanic. The African American and Hispanic caregivers were younger than White caregivers. After controlling for sociodemographic factors, there was no difference by race/ethnicity on the outcome measures. No significant differences were found among the White, African American, and Hispanic caregivers on measures of the caregiving experience.

Financial Concerns

Breast cancer imposes substantial burdens on caregiving, as well as the financial burden that is associated with the onset and treatment of the disease. Cancer frequently follows an unpredictable course, with patients experiencing numerous disruptions in their

lives. The enormous financial burdens that accompany the onset and subsequent treatment of cancer become even more overwhelming.

It is estimated that the United States lifetime per patient costs of breast cancer range from \$20,000 to \$100,000 (Campbell & Ramsey, 2009). Much of this cost reflects hospital stays, physician visits, and chemotherapeutic agents which may be fully or partially covered by insurance. There are out-of-pocket costs and copayments that are not reimbursed or partially reimbursed by third party payers. Such costs can impose devastating financial burdens on the patient and her partner (Emanuel et al., 2000). Emanuel et al.'s (2000) study to determine the impact of economic and noneconomic burdens of illness on 998 terminally ill patients and 893 caregivers found 44.9% of patients and caregivers reported subjective economic burdens.

Breast cancer can have great financial implications, especially for low-income families. One or both partners may be forced to stop working and costly alterations to the home may be required (Rees et al., 2001). Yun et al. (2004) evaluated the association of burdens and the caregiver's quality of life in a group of 704 Korean caregivers of patients with breast, lung, stomach, colon, and rectal cancer. The findings revealed that economic issues were more strongly correlated with quality of life than other variables.

Poor people are more likely to be diagnosed with cancer when the disease is advanced and treatment options are significantly more limited. Limited access to medical care carries the additional risk of denied access to community resources, which often are made through referrals from the health care system (Rees et al., 2001). Guidry, Aday, Zang, and Winn (1998) conducted a four-year research study on 593 patients with breast,

colon, cervical, and prostate cancer, and lymphoma to examine the racial/ethnic differences in insurance coverage, insurance barriers, and the role of treatment costs as barriers to cancer treatment. The results revealed that maintaining and affording insurance premiums were more of a barrier in African Americans. More African Americans reported having been denied insurance coverage when they changed jobs compared with Whites and Hispanics.

For the middle-class family with insurance, as medication costs increase (whether they are covered or not), financial deprivations accumulate as out-of-pocket expenditures increase due to required insurance deductibles and copayments, and wages lost because of aspects of the treatment. Therefore, even those who are insured can be financially devastated by substantial gaps in coverage. A diagnosis of cancer compounds the struggle for survival and introduces new financial, physical, and psychological demands (Berkman & Sampson, 1993).

Faith

A serious illness such as breast cancer is an event that may bring to the forefront the importance of the male partner's faith and religious involvement.

The meanings of faith and spirituality have often been debated, with no scholarly consensus of their meanings and roles in everyday life (Mattis, 2000). Faith has been defined as a trusting relationship with God or a supreme being which fosters meaning and hope in life (Meraviglia, 1999). In 1997, Dyson, Cobb, and Forman published a comprehensive review of the meaning of spirituality. Their findings yielded key elements and themes for the definition of spirituality, indicating that faith and faith practices may

be considered as major components of spirituality. This definition was utilized in this research.

Research studies have also documented the importance of faith and religious practices as important components which can extend to every aspect of most African Americans' lives (Mattis, 2000). Faith and religious practices have been shown to distinctly influence African Americans' health beliefs, practices, and medical outcomes (Newlin, Knaft, & Melkus, 2002).

According to Ferraro and Koch (1994), African Americans are more likely than Whites to turn to religion as a coping resource when faced with health challenges. Research studies conducted on African Americans (Ellison, 1993; Ellison, Gay, & Glass, 1989; Krause & Van Tran, 1989; Levin, Chatters, & Taylor, 1995) revealed a positive correlation between spiritual and religious involvement with health and life satisfaction. Support is added to this statement by the results of a qualitative research study conducted by Taylor (2003) of 28 African American and European American patients with cancer and their family caregivers. The study assessed their spiritual needs, and findings revealed caregivers had spiritual needs similar to those of the patients.

A longitudinal and descriptive study conducted at 3 and 30 days of 50 spouses of women with breast cancer revealed spouses reporting that the strength they received from their religious faith helped them to cope with their wives' breast cancer, as it gave a sense of purpose and meaning to their wives' illness (Northouse, 1989).

Additionally, a descriptive study of 461 spouses of cancer patients was conducted to examine the effects of spirituality between caregiving stress and their mental and

physical health. The findings revealed that maintaining faith and finding meaning in the experience buffered the adverse effects of caregiving stress on mental health (Colgrove, Kim, & Thompson, 2007).

According to the *U.S. Religious Landscape Survey* conducted in 2007 by the Pew Forum on Religion and Public Life (2008), African Americans are among the most likely to report a formal religious affiliation: 87% of African Americans described themselves as belonging to one religious group or another. The *Landscape Survey* also found that nearly 8 in 10 African Americans (79%) say religion is very important in their lives, compared with 56% among all U.S. adults. In fact, even a large majority (72%) of African Americans who are unaffiliated with any particular faith stated religion plays at least a somewhat important role in their lives; nearly half (45%) of unaffiliated African Americans stated religion is very important in their lives—roughly three times the percentage who stated this among the religiously unaffiliated population overall (16%).

Positive Adaptation

Receiving a diagnosis of cancer is stressful for a patient and her partner as they must adapt to the shock and uncertainty of the diagnosis and treatment modalities to follow. Lazarus and Folkman (1984) classified coping strategies as either problem focused or emotion focused. Researchers have also classified coping strategies according to outcome in terms of their functional or adaptive value and their effectiveness in terms of elimination of stressors and distress, as well as preservation of social functioning and a sense of well-being (BenZur, 2001).

Morse and Fife (1998) studied 188 partners of cancer patients after patients' diagnoses, at first remission, after recurrence, and when patients had advanced disease. The ethnicities were not defined. They found that avoidance was related to poorer adaptation among partners, while the strategy of denial was adaptive and was associated with better adjustment. In this study denial was defined as the extent to which partners minimized the impact of the illness on their everyday lives, whereas avoidance was measured by, for example, sleeping more than usual, taking medications or using alcohol, and not letting others know how they were feeling.

A 2003 research study conducted by Edwards and Clarke (2004) in Melbourne, Australia, on 48 newly diagnosed cancer patients with 59% breast cancer, 25% colorectal cancer, and 16% prostate cancer, and 48 families, examined depression and anxiety. Results revealed that family members who were able to act openly, express feelings directly, and solve problems effectively had lower levels of depression. Direct communication of information was associated with lower levels of anxiety.

Ptacek, Ptacek, and Dodge (1994) conducted a study on breast cancer patients and their husbands addressing five types of coping: problem focused, seeking support, self-blame, wishful thinking, and avoidance. Problem focused was the most common among husbands; seeking support and was strongly related to their better psychological adjustment. The strategies of self-blame, wishful thinking, and avoidance had a negative impact on the mental health of husbands and wives.

The consequences of a woman's breast cancer experience are not all negative. Most partners cope well with the diagnosis and caregiving role (Pitceathly & Maguire,

2003). Studies have identified positive aspects of the role such as increased self-esteem, pride, gratification, and feeling closer to their spouse (Folkman, Chesney, Collette, Boccellari, & Cooke, 1996; Kramer, 1997). Some researchers have suggested that the responsibility of caring for one's ill partner may confer a sense of meaning to life and this, in turn, may augment the partner's global quality of life (Axelsson & Sjoden, 1998). In a study of caregivers of multiple sclerosis patients, many partners reported positive aspects of their roles and described how being a caregiver made them more caring toward others (Knight, Devereux, & Godfrey, 1997).

Nijboer et al. (1999) found an inverse correlation between the educational level of the caregiver and the positive impact of caregiving. In this study, those with lower levels of education were able to derive more self-esteem from caregiving.

Community Research on African American Males

The challenges of recruiting African American male participants for research studies are well known (Ford, Havstad, & Davis, 2004; Jones, Steeves, & Williams, 2009; Plowden, Wendell, Vasquez, & Kimani, 2006).

Previous community research (Campbell et al., 2006; Lassater, Wells, Carleton, & Elder, 1996) has shown that churches can be rich recruitment sites for African Americans. Churches have relatively large memberships and are likely to facilitate widespread diffusion of information because many church members belong to other organizations in the community (Lassater et al., 1996). In addition, it is known that research and interventions with African Americans are most effective when the interventions incorporate spiritual and cultural contextualization (Campbell et al, 2006).

Summary

This literature review synthesized research on the domains of quality of life of partners of cancer patients. There is considerable research on the diverse variables that affect the potential positive and negative effects on the partner's quality of life. However, the literature review revealed a dearth of research on the association between racial/ethnic group and the quality of life of the spouses/partners of breast cancer patients. This limited amount of research on partners of African American women with breast cancer supported the rationale for conducting this study.

3. METHODOLOGY

This chapter includes an overview of the study, research questions, research design, population and sample, instruments, data collection procedures, data analysis, ethical considerations, and summary.

Overview

This research examined the self-reported quality of life of a sample of partners of African American women with breast cancer. The results were used to make inferences for this ethnicity about the quality of life during the shared breast cancer experience.

Research Questions

1. What are the demographic characteristics of African American women with breast cancer and their partners?
2. What is the level of self-reported quality of life in the partners of African American women with breast cancer?
3. Is there any relationship between the quality of life domains—burden, disruptiveness, positive adaptation, and financial concerns—of the partners of African American women with breast cancer and the following?
 - a. Age
 - b. Years of education
 - c. Employment status

- d. Marital status
- e. Length of time with partner
- f. Stage at diagnosis
- g. Type of surgery
- h. Faith

Research Design

A quantitative, descriptive study design examined the relationships among the dependent variable, quality of life, and the independent variables which include demographics, disruptiveness, burden, financial concerns, and positive adaptation. This research design was appropriate because it allowed for examination of the interrelationships among variables. In addition, the design has the strength of realism which may allow for practical problem solving (Polit & Beck, 2008).

Population

The target population for the proposed research was the partners of African American women with breast cancer living in a large city and suburbs of the United States Mid-Atlantic Region. The U.S. Census Bureau (2012) reports that this region has some of the top 10 cities with large populations of African Americans in the United States, with 326,312 residing in the large city and 113,108 in the suburban areas. According to the National Cancer Institute (2012), the incidence rate of breast cancer per 100,000 African American women in the large Mid-Atlantic city was 130.9; in the suburban areas the rate was 121.1. The incidence rate for the United States was 124.9 per 100,000. The estimated target population was 544.

The study sample included African American/Black males, 18 years of age or older, who had a minimum of a sixth grade education, and were a husband or cohabitating partner of an African American/Black female who had been diagnosed with breast cancer. Same-sex partners, partners who were not African American, and partners with less than a sixth grade education were excluded.

Sample Size

Power analysis to estimate sample size was performed using Cohen's ANOVA tables (1988, p. 93, Table 3.3.5). Given $\alpha = 0.05$, effect size of 0.30, and a desired power of .85, it was determined the minimum sample size of 96 participants was required. Previous research (Wagner et al., 2005) predicted an effect size in the range of 0.10 to 0.20. To increase the power of the study, the recruitment strategy, as described below, included multiple sources to account for the well-known challenges of recruiting African American male participants (Ford, Havstad, & Davis, 2004; Jones, Steeves, & Williams, 2009; Plowden, Wendell, Vasquez, & Kimani, 2006). After months of trying and using multiple forms of recruitment, the minimum calculated sample size of 96 participants was not obtained. The actual sample size is 30 couples which reduced the generalizability of this study.

Instruments

The study utilized three questionnaires: (a) a researcher-developed, closed-ended socio demographics questionnaire for the woman with cancer; (b) a similar questionnaire for her male partner, and (c) the Caregiver Quality of Life Index-Cancer (CQOLC) (Weitzner et al., 1999). The questionnaire for the woman with cancer (Appendix A)

included 25 questions related to age; racial/ethnic group; employment, marital, educational, and income status; history of breast and cancer treatment; faith; perceived influence of faith on coping with breast cancer; and the need for assistance with activities of daily living during cancer for treatment. The questionnaire for the woman's male partner (Appendix B) included 17 questions related to age; racial/ethnic group; employment, marital, and educational status; faith; and perceived influence of faith on the ability to provide support during the partner's breast cancer diagnosis and treatment. As indicated by asterisks on Appendix A, a number of the questions were adapted from the National Cancer Institute's Health Information National Trends Survey (2007).

The Caregiver Quality of Life Cancer Scale was developed by Weitzner et al. (1999) at the M.D. Anderson Cancer Center in Houston, TX. This study sample included caregivers of patients with breast, lung, gastrointestinal, and genitourinary cancers. The CQOLC (Appendices C, D, and E; used with permission) is a pen/pencil 35 item, self-reported questionnaire with a 5-point Likert scale. The developer reports the need for a sixth grade reading level, and an estimated time of 10 minutes to complete the questionnaire.

In this current study, the Caregiver Quality of Life questionnaire assessed the multidimensional construct of perceived quality of life utilizing four dimensions. The factors of measurement included burden (questions 9, 11, 14, 17, 18, 19, 20, 25, 31, 33), disruptiveness (questions 1, 3, 5, 21, 24, 26, 29), positive adaptation or response shift (questions 10, 12, 16, 22, 27, 28, 34), and financial burden (questions 6, 7, 8). The maximum total score on the CQOLC is 140 (Edwards & Ung, 2002). The higher the score

on the CQOLC, the better the quality of life. The instrument has a test–retest reliability correlation coefficient of 0.95 and a Cronbach’s alpha coefficient of 0.91 (Weitzner et al., 1999).

Three African American male academicians who have experience with cancer and/or have been a caregiver reviewed the CQOLC instrument for content validity (Appendix F).

The CQOLC has been used in numerous types of cancer studies (Clark et al., 2006; Juarez, 2003; Kim, Baker, & Spellers, 2007; Pimenta, Costa, Goncalves, & Alvarez, 2009; Tamayo, Broxson, Munsell; & Cohen, 2010); and in quality of life cancer research with diverse populations of Hispanic, Portugese, and Taiwanese subjects (Juarez, 2003; Pimenta et al., 2009; Chen, Chu, & Chen, 2004). Prior to this current study, this instrument had not been used for specific research focusing on African Americans (M. A. Weitzner, personal communication, September 20, 2010).

Data Collection Procedures

A pilot study ($N = 10$) was conducted to evaluate the procedures, participant recruitment strategy, and the quality of the instruments to be used (Polit & Beck, 2008). It was determined that the procedures, recruitment strategy and instrument questions were satisfactory. The surveys for the ten couples were included in the research.

A multifaceted approach for recruitment of participants was utilized. Participants were solicited from sources known to provide access to large numbers of African Americans and women with breast cancer: African American churches, beauty salons,

barber shops, and breast cancer support groups. Flyers provided information about the study, and word-of-mouth referrals were also encouraged (Appendix G).

As noted earlier, previous community research (Campbell et al., 2006; Lassater, Wells, Carleton, & Elder, 1996) has shown that churches can be rich recruitment sites for African Americans. Churches have relatively large memberships and are likely to facilitate widespread diffusion of information because many church members belong to other organizations in the community (Lassater et al., 1996). In addition, it has been established that research and interventions with African Americans are most effective when the interventions incorporate spiritual and cultural contextualization (Campbell et al., 2006). The researcher worked in partnership with church ministers to discuss the study's significance and to develop church-specific recruitment strategies that involved disseminating publicity materials and on-site data collection by the researcher.

After permission to conduct the study was received, the researcher, either at the site or via telephone, explained the study to the participants and invited breast cancer patients and their partners to participate.

Informed consents were obtained (Appendix H) and survey packets were either distributed in person or mailed via USPS or electronic mail. The packets contained an introductory letter about the study, a consent form (if it had not been received), the three study questionnaires, and a stamped self-addressed return envelope. A record was maintained of all breast cancer patients who were approached about the study and who agreed to complete the study questionnaires. A reminder telephone call was placed to the participants by the researcher within one week of conversing with the participant.

Recruitment flyers were disseminated in African American beauty salons, barbershops, and neighborhoods.

Data Analysis

The data from this study required the use of descriptive measures, Bivariate Spearman-Rank correlations and Kruskal-Wallis one-way analysis of variance (ANOVA) statistical tests were used. The was Kruskal-Wallis one-way ANOVA was used to compare groups on demographic variables and on the four domains related to the aims of the study. The frequency, percentage, mean, and standard deviation were used for data analysis of research questions one and two. The Kruskal-Wallis one-way ANOVA was used to analyze the relationship between employment, marital status, stage of disease at diagnosis, and types of surgery with the four domains of quality of life (burden, disruptiveness, positive adaptation, and financial concerns).Data for research question three necessitated the use of Bivariate Spearman-Rank correlations to analyze age, years of education, and length of time with partner as related to the quality of life domains of partners of African American women with breast cancer. The SPSS software program was used to analyze the data.

Ethical Considerations

Permission to conduct the study was obtained from the George Mason University Human Subject Review Board (HSRB) (Appendix I) and from the selected breast cancer clinics. After initial approval the protocol was reviewed by the HSRB in 12 months. The researcher monitored and collected the data. The study materials included a cover letter which explained the purpose of the study and the participant's anonymity, an informed

consent, and the three data collection instruments. The informed consent explained the research study's purpose, procedures, risk, and benefits, as well as assurances about the participants' anonymity and freedom to withdraw from the research study at any time without any recrimination. The researcher's contact information was also provided.

Summary

This chapter provided information regarding the research questions, the research design, population of interest, sample size, survey instruments, procedures for data collection, analysis and the ethical considerations employed to conduct the study.

4. ANALYSIS OF DATA

This chapter presents research study questions one and two followed by supporting statistical data and tables. Research question three is addressed by providing partner answers to the total Caregiver Quality of Life Index-Cancer (CQOLC) questionnaire, its domain scores, nonparametric tests, and tables.

The purpose of this study was to explore the level of self-reported quality of life of partners of African American women with breast cancer. The study utilized three questionnaires: a demographics survey instrument for the African American woman with breast cancer, one for her male African American partner, and the CQOLC for her male African American partner. The demographics questionnaire for the woman contains eight questions specifically related to the time of diagnosis, stage, surgery, and treatment. The remaining 17 questions for the woman and man are the same and concern sociodemographic information.

The Caregiver Quality of Life Index-Cancer instrument (CQOLC) (Weitzner et al., 1999) is a 35-item, self-reported questionnaire used to measure the male partners' quality of life using four domains: Burden, Disruptiveness, Positive Adaptation, and Financial Concerns. The CQOLC has a 5-point Likert format that ranges from 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit), to 4 (very much). Ten items relate to burden, seven to disruptiveness, seven to positive adaptation, three to financial concerns,

and eight single items to additional factors: disruption of sleep, satisfaction with sexual functioning, day-to-day focus, mental strain, informed about illness, protection of patient, management of patient's pain, and family interest in caregiving. The CQOLC scale is scored by adding up the score on each item to yield a total score for the instrument. Scores can range from 0-140. For all items and domains that measure quality of life, a higher score represents a better quality of life (Weitzner et al., 1999).

Survey packets totaling 729 were disseminated at an African American breast cancer support group national conference, urban men against breast cancer support group, hospital-based breast cancer support groups, African American churches and to physician referrals. Following research funding, a participant request and this study's Survey Monkey link, https://www.surveymonkey.com/s/Demographics_and_Caregiver_Quality_of_Life_Survey (Appendix J), was also sent to members of two of the African American support groups. The recruitment announcement was featured on their websites.

Couples were offered two \$20.00 Visa gift certificates to complete the research questionnaires. Post-funding couple responses were four. Thirty-eight survey packets were received via mail, and 21 were received via Survey Monkey. Twenty-one questionnaires received via mail were excluded due to incomplete information and women widowers responding. Eight Survey Monkey responses were excluded due to race or ethnicity and noncompletion of components of the questionnaires. The final dataset consists of 30 couples (60 participants). All study participants in the final sample are African American. All partners of women with breast cancer are male.

Thus, after months of trying and using multiple forms of recruitment, the minimum calculated sample size of 96 participants was not obtained. Extreme problems gaining the trust and confidence of African American couples, specifically African American men, made recruiting difficult. This can be supported by research studies conducted which assessed the views, attitudes, and barriers African Americans have toward research participation. African Americans' distrust of the government and the medical research establishment was cited in a study of focus groups conducted by Stark et al (2002). This study was conducted to assess the knowledge and attitudes of minorities with regard to participation in research. The study consisted of 26 participants: 19 African American men and women and 7 Native American men and women. African American men voiced the greatest distrust, citing the Tuskegee Syphilis Experiment as their reason.

A qualitative study of 33 African Americans was conducted to explore the reasons for low participation of African Americans in research. The study revealed that the participants described distrust of the medical community as a prominent barrier to research participation (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999). This is further supported by a qualitative research study conducted by Freimuth et al. (2001) of 60 African Americans. The study examined their knowledge and attitudes toward medical research. One of the study's findings revealed that a substantial barrier to recruitment was distrust of researchers. One participant in the study stated that for her to trust researchers she would need to make sure that, "White people are also in the study" (p. 806).

In addition to the documented challenges of recruiting African American males for research, those electing not to participate may have been hesitant to respond due to the very sensitive nature of the topic of breast cancer. Additionally, privacy may have been a concern, despite this study's recruitment letter and informed consent's assurances of anonymity. This was evidenced in a conversation held with the partner of an African American woman with breast cancer who stated, "This is private. No one needs to know our business!"

Conversations regarding the challenges of participant recruitment and obtaining the calculated sample size were discussed with the dean of the researcher's nursing doctoral program, the researcher's dissertation committee chair, dissertation committee members, and input was obtained from experienced researchers of this population. With their support it was determined that this research study would be allowed to move forward.

Results

Research Question 1: Demographics

Research Question 1 asked: "What are the demographic characteristics of African American women with breast cancer and their partners?" The general demographic characteristics of data for this sample ($n = 30$) are illustrated in Tables 1, 2, and 3.

The median age in years for women was 50.5 and for men 58.5. The majority of the couples, 88.3%, are married; one couple had never been married and one couple was living together. Twenty-two percent of the sample had been in the relationship an average of 22 years.

Answers to the question “Were you previously divorced, separated, or living apart from your partner/spouse prior to your breast cancer diagnosis?” reflected that 98.3% of the couples were living together prior to the breast cancer diagnosis. The highest level of education attained showed 20% of the men and 16.7% of the women—or 36.7% of the sample—had greater than 16 years of schooling. Only one male and one female did not graduate or had less than 12 years of schooling. One female did not have health insurance, but 37.9% of the men and 41.4% of the women had private insurance. Employment status illustrates 40% of the men and 45.7% of the women were employed for wages. Change in employment since breast cancer diagnosis revealed 11.7% of men, and 10.0% of women—or 21.7% of the sample—with a change. The median annual total household income was \$80,000 women, \$77,628 for men. Fifty percent of the couples had at least one child under the age of 18 residing in the household, although the reported average number of people in the household was two. Sixty-five percent of the couples reported that others living in the household contributed to the household income. Three men and three women did not report a religion/faith, and 53.3% of men and women selected Baptist. Partners’ answers to question 11 of the partner demographics questionnaire, “Has your faith or religion assisted you in coping with your wife’s breast cancer experience?”, revealed 60% of the partners answered that their faith or religion was a great deal of help, 23% answered that their faith or religion was somewhat helpful, and 17% answered that their faith or religion was not helpful.

Table 1

Descriptive Statistics Table 1: Continuous Demographic and Relationship Variables

Demographic Variable	Percentage of Men (<i>n</i> = 30)	Percentage of Women (<i>n</i> = 30)	Percentage of Men and Women Combined (<i>N</i> = 60)
Age (years)			
Mean (\pm SD)	58.13 (\pm 9.92)	54.87 (\pm 10.97)	56.5 (\pm 10.5)
Median	58.5	50.5	54
Mode	49	47	[multiple modes exist]
Minimum	40	36	36
Maximum	79	80	80
Relationship length (years)			
Mean (\pm SD)	22.38 (\pm 12.14)	22.39 (\pm 12.13)	22.38 (\pm 12.03)
Median	20	20	20
Mode	20	20	20
Minimum	3	3	3
Maximum	59	59	59
Average annual household income (in USD)			
Mean (\pm SD)	96,939.10 (\pm 66,310.79)	97,550 (\pm 66,308.36)	97,244.55 (\pm 6,5745.95)
Median	77,628	80,000	80,000
Mode	75,000	75,000	75,000
Minimum	0	0	0
Maximum	250,000	250,000	250,000
Age of youngest child in household (years)			
Mean (\pm SD)	9.5 (\pm 3.85)	9.5 (\pm 3.85)	9.85 (\pm 3.74)
Median	10	10	10
Mode	10	10	10
Minimum	4	4	4
Maximum	16	16	16

Table 2

Descriptive Statistics Table 2: Categorical Demographic and Relationship Variables

Demographic Variable	Men		Women		Men and Women Combined	
	Frequency	Percentage (n = 30)	Frequency	Percentage (n = 30)	Frequency	Percentage (N = 60)
Marital Status						
Married	27	90.00%	26	86.67%	53	88.33%
Never been married	1	3.33%	1	3.33%	2	3.33%
Living with a partner	1	3.33%	2	6.67%	3	5.00%
Living apart from partner/spouse	1	3.33%	1	3.33%	2	3.33%
Precancer partner relationship: Response to the question, "Were you previously divorced, separated, or living apart from your partner/spouse prior to your breast cancer diagnosis?"						
Yes	0	0.00%	1	3.33%	1	1.67%
No	30	100.00%	29	96.67%	59	98.33%
Religion						
None stated	3	10.00%	3	10.00%	6	10.00%
Baptist	16	53.33%	16	53.33%	32	53.33%
Methodist	1	3.33%	3	10.00%	4	6.67%
Seventh Day Adventist	1	3.33%	1	3.33%	2	3.33%
Episcopal	1	3.33%	0	0.00%	1	1.67%
Roman Catholic	1	3.33%	3	10.00%	4	6.67%
Christian (nondenominational)	6	20.00%	3	10.00%	9	15.00%
African Methodist Episcopal	1	3.33%	1	3.33%	2	3.33%
Employment Status						
Employed for wages	18	60.00%	17	56.67%	35	58.33%
Self-employed	1	3.33%	0	0.00%	1	1.67%
Unemployed	0	0.00%	3	10.00%	3	5.00%
Unable to work	2	6.67%	1	3.33%	3	5.00%
Retired	9	30.00%	9	30.00%	18	30.00%

(continued)

Table 2. *Descriptive Statistics Table 2: Categorical Demographic and Relationship Variables (continued)*

Demographic Variable	Men		Women		Men and Women Combined	
	Frequency	Percentage (n = 30)	Frequency	Percentage (n = 30)	Frequency	Percentage (N = 60)
Health Insurance Type						
None (uninsured)	0	0.00%	1	3.33%	1	1.67%
Private health insurance	22	73.33%	24	80.00%	46	76.67%
Medicare	5	16.67%	3	10.00%	8	13.33%
Covered by more than one type of health insurance	2	6.67%	2	6.67%	4	6.67%
No response/missing	1	3.33%	0	0.00%	1	1.67%
Do others in household contribute income?						
Yes	16	53.33%	23	76.67%	39	65.00%
No	14	46.67%	7	23.33%	21	35.00%
Number of people in household						
1	2	6.67%	2	6.67%	4	6.67%
2	17	56.67%	16	53.33%	33	55.00%
3	2	6.67%	3	10.00%	5	8.33%
4	7	23.33%	6	20.00%	13	21.67%
5	2	6.67%	2	6.67%	4	6.67%
7	0	0.00%	1	3.33%	1	1.67%
Number of people under age 18 in household						
0	21	70.00%	20	66.67%	41	68.33%
1	3	10.00%	3	10.00%	6	10.00%
2	6	20.00%	6	20.00%	12	20.00%
3	0	0.00%	1	3.33%	1	1.67%

Table 3

Respondent Highest Level of Education Attained by Breast Cancer CQOLC Survey Format (Electronic or Paper Questionnaire)

Education Level	CQOLC Survey Format						Overall Total
	Paper			Electronic			
	Men	Women	Total	Men	Women	Total	
Less than high school (did not graduate; <12 years schooling)	1	1	2	0	0	0	2
High school (12 years of schooling)	4	3	7	3	5	8	15
Associate’s degree; some college (12 to 16 years of schooling, not inclusive)	5	0	5	2	3	5	10
College degree (16 years of schooling)	2	7	9	1	0	1	10
Graduate or medical school (>16 years of schooling)	5	5	10	7	5	12	22
No response (missing)	0	1	1	0	0	0	1
Total	17	17	34	13	13	26	60

Note. N = 60 (30 couples = 30 men and 30 women).

In an effort to examine the sociodemographics of this study's participants with that of the Overall United States population information from the 2011 U.S.Census Bureau report was checked. The report showed that there are 308.7 million African Americans in the United States. Of this number 67.4% of this population are women 18 years or older.

The marital status for African Americans reflects 31.3% of the population are married, 46% of the female population has never been married and of those only 26%

who are married have a spouse that is present. The median household income for this population is reported as \$41,772.00.

Educational statistics for African American males showed that 28.4% are less than high school graduates, 71.6% are high school graduates or have more education, and 18% have a bachelor's degree or more. Statistics for African American females show that 15% are less than a high school graduate, 85% are high school graduates or have more education, 21.4% have a bachelor's degree or more.

With regards to employment the report showed that 83.7% of African American males and 78.9% of African American females are employed full time.

Health insurance for African American males 18-64 years revealed that 67.7% are insured 32.3% are uninsured. For African American women 75.9% are insured and 24.1% are uninsured.

The next two tables provide data with regard to the cancer-related characteristics of the African American women in the sample. Tables 4 and 5 illustrate that 40% of the sample were diagnosed with breast cancer at stage II; 13.3% were diagnosed in both 2008 and 2011.

Table 4

Stage of Breast Cancer at Time of Diagnosis

	Frequency	Percentage	Cumulative Percentage
Stage 0 DCIS	2	6.7%	6.7%
Stage I	11	36.7%	43.3%
Stage II	12	40.0%	83.3%
Stage III	5	16.7%	100.0%
Total	30	100.0%	

Note. DCIS = Ductal carcinoma in situ.

Table 5

Year Breast Cancer First Diagnosed

Year	Frequency	Percentage	Cumulative Percentage
1986	1	3.3%	3.3%
1995	1	3.3%	6.7%
1998	1	3.3%	10.0%
2000	3	10.0%	20.0%
2003	1	3.3%	23.3%
2004	3	10.0%	33.3%
2005	2	6.7%	40.0%
2006	2	6.7%	46.7%
2007	3	10.0%	56.7%
2008	4	13.3%	70.0%
2009	3	10.0%	80.0%
2010	2	6.7%	86.7%
2011	4	13.3%	100.0%
Total	30	100.0%	

Note. *n* = 30 women.

Table 6 illustrates 30% of the women in the sample had mastectomies, 56.6% had lumpectomies, and 13.3% had both a lumpectomy and a mastectomy. Nonsurgical breast

cancer treatment received by the research study participants, as reflected in Table 7, revealed 23.3% had chemotherapy only, 6.6% had radiation therapy only, and 50% received both. Only 3.3% of the sample had hormone therapy (HT).

Table 6

Type(s) of Breast Cancer Surgery (Ever) Received

Frequency Statistics	Lumpectomy only (ever)	Mastectomy only (ever)	Both lumpectomy and mastectomy (ever)	Total
Count	17	9	4	30
Percentage	56.67%	30.00%	13.33%	100.00%

Table 7

Type(s) of Nonsurgical Breast Cancer Treatment (Ever) Received

Nonsurgical Breast Cancer Treatment (Ever) Received	Count	Percentage
None	5	16.67%
Radiation Therapy only	2	6.67%
Chemotherapy only	7	23.37%
HT only	1	3.33%
Both Radiation and Chemotherapy only	15	50.00%
Radiation, Chemotherapy, and HT	0	0.00%
Total	30	100.00%

Note. HT = hormone therapy.

Research Question 2: Partner Quality of Life

Research Question 2 asked: “What is the level of self-reported quality of life in the partners of African American women with breast cancer?”

The overall level of the self-reported quality of life of the African American male partners of African American women with breast cancer in this sample is quantified via the average total CQOLC score. This is the total CQOLC score averaged across all 30 male partners. The maximum possible score on the CQOLC is 140. The mean total CQOLC score is 74.2 ± 15.55 (mean \pm SD). The median of the total CQOLC scores is 77 as presented in Table 8. A higher total CQOLC score represents a better quality of life.

Table 8

Overall and Domain-Specific CQOLC Scores for the Partners of African American Women With Breast Cancer

		CQOLC Total Score ^b	CQOLC Burden Total Score ^c	CQOLC Disruptiveness Total Score ^d	CQOLC Positive Adaptation Total Score ^e	CQOLC Financial Concerns Total Score ^f
Count	Valid	30	30	30	30	30
	Missing	0	0	0	0	0
Mean		74.8000	29.2333	24.2000	10.9000	10.4667
Median		77.0000	29.5000	26.0000	11.0000	11.5000
Mode		83.00	36.00 ^a	28.00	11.00 ^a	12.00
Std. Deviation		15.55058	7.37509	4.89475	6.61425	2.09652
Minimum		0.00	0.00	0.00	0.00	0.00
Maximum		140.00	40.00	28.00	28.00	12.00

a. Multiple modes exist. The smallest value is shown

b. CQOLC Total Score = Sum of scores for questions 1-35

c. CQOLC Burden Total Score = Sum of scores for questions 9, 11, 14, 17, 18, 19, 20, 25, 31, 33

d. CQOLC Disruptiveness Total Score = Sum of scores for questions 1, 3, 5, 21, 24, 26, 29

e. CQOLC Positive Adaptation Total Score = Sum of scores for questions 10, 12, 16, 22, 27, 28, 34

f. CQOLC Financial Concerns Total Score = Sum of scores for questions 6, 7, 8

There are four quality of life domains measured by the CQOLC instrument for the African American male caregivers of the African American women with cancer: (a) Burden (questions 9, 11, 14, 17, 18, 19, 20, 25, 31, 33), (b) Disruptiveness (questions 1, 3, 5, 21, 24, 26, 29), (c) Positive Adaptation (questions 10, 12, 16, 22, 27, 28, 34), and (d)

Financial Concerns (questions 6, 7, 8). The survey participant's total score within a given domain was calculated by summing his scores across all of the questions within that domain with the exception of the positive adaptation domain. Questions for the positive adaptation domain, 10, 12, 16, 22, 27, 28, and 34, were reverse coded per instrument instructions. Questions 2, 4, 13, 15, 23, 30 and 32 were not included in any particular domain.

Hence, the range of possible total scores for Burden, Disruptiveness, Positive Adaptation, and Financial Concerns were [0, 40], [0, 28], [0, 28], and [0, 12], respectively. The average Burden total CQOLC score for the male caregivers was 29.23 ± 7.38 (mean \pm SD), with a median Burden total score of 29.5 (Table 8, column 2). The average Disruptiveness total CQOLC score for the male caregivers was 24.2 ± 4.89 (mean \pm SD), with a median total score of 26 (Table 8, column 3). The average Positive Adaptation total CQOLC score for the male caregivers was 10.9 ± 6.61 (mean \pm SD), with a median total score of 11 (Table 8, column 4). The average Financial Concerns total CQOLC score for the male caregivers was 10.46 ± 2.0 (mean \pm SD), with a median total score of 12 (Table 8, column 5).

CQOLC Cronbach Alpha's internal consistency reliability statistics for Domain 1: Burden is detailed in Table 9 as .785 in comparison to the CQOLC Cronbach Alpha's instrument Score of .89 (Table 10). Table 9 reflects the Cronbach Alpha's score for Domain 2: Disruptiveness as .784. The CQOLC Cronbach Alpha's instrument score is .83 (Table 10). The CQOLC Cronbach Alpha's instrument score for Domain 3: Positive Adaptation is .73 as illustrated in Table 10. The reason for this score is due to the low

number of items. For comparison, Table 11 reflects .83 as the Cronbach Alpha score for the CQOLC scale used in a research study of 237 caregivers of patients with various forms of cancer (Bektas & Ozer, 2009).

Table 9

CQOLC Internal Consistency, Reliability: Cronbach's Alpha by Domain - Present Study

Domain	Cronbach's Alpha	n of Items
1: Burden	.785	10
2: Disruptiveness	.784	7
3: Positive Adaptation	.758	7
4: Financial Concerns	.585	3

Table 10

*CQOLC Internal Consistency, Reliability: Cronbach's Alpha by Domain - Instrument**

Domain	Cronbach's Alpha	n of Items
1: Burden	.89	10
2: Disruptiveness	.83	7
3: Positive Adaptation	.73	7
4: Financial Concerns	.81	3

*The Caregiver Quality of Life Index-Cancer (CQOLC) scale development and validation instrument to measure quality of life of the family caregiver of patients with cancer (Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999).

Table 11

*CQOLC Internal Consistency, Reliability: Cronbach's Alpha by Domain - Bektas and Ozer**

Domain	Cronbach's Alpha	n of Items
1: Burden	.83	10
2: Disruptiveness	.79	7
3: Positive Adaptation	.73	7
4: Financial Concerns	.77	3

*Reliability and validity of the Caregiver Quality of Life Index-Cancer (CQOLC) scale in Turkish cancer caregivers (Bektas & Ozer, 2009).

The CQOLC domain item-specific summary statistics are listed in Tables 12, 13, 14, and 15. Table 16 shows CQOLC item-specific summary statistics for questions that do not load on to a specific domain.

Table 12

CQOLC Domain 1: Burden: Item-Specific Summary Statistics

Question #	CQOLC Question	Item Response Frequencies (raw scores) Count (%)					Mean Response	Total Number of Responses Count (%)
		0	1	2	3	4		
Q9	I fear my loved one will die.	14 (46.7%)	4 (13.3%)	4 (13.3%)	7 (23.3%)	1 (3.3%)	1.233	30 (100%)
Q11	My level of stress and worries has increased.	13 (43.3%)	7 (23.3%)	5 (16.7%)	2 (6.7%)	3 (10%)	1.167	30 (100%)
Q14	I feel/felt sad.	12 (40%)	8 (26.7%)	2 (6.7%)	7 (23.3%)	1 (3.3%)	1.233	30 (100%)
Q17	I feel/felt guilty.	21 (70%)	5 (16.7%)	1 (3.3%)	2 (6.7%)	1 (3.3%)	.567	30 (100%)
Q18	I feel/felt frustrated.	17 (56.7%)	8 (26.7%)	2 (6.7%)	2 (6.7%)	1 (3.3%)	.733	30 (100%)
Q19	I feel/felt nervous.	15 (50%)	8 (26.7%)	5 (16.7%)	1 (3.3%)	1 (3.3%)	.833	30 (100%)
Q20	I worry about the impact my loved one's illness has had on my children or other family members.	12 (40%)	5 (16.7%)	5 (16.7%)	6 (20%)	2 (6.7%)	1.367	30 (100%)
Q25	I fear/feared the adverse effects of treatment on my loved one.	13 (43%)	5 (16.7%)	8 (26.7%)	1 (3.3%)	3 (10%)	1.200	30 (100%)
Q31	It upsets/upset me to see my loved one deteriorate.	9 (30%)	4 (13.3%)	5 (16.7%)	6 (20%)	6 (20%)	1.867	30 (100%)
Q33	I am/was discouraged about the future.	22 (73.3%)	2 (6.7%)	4 (13.3%)	1 (3.3%)	1 (3.3%)	.567	30 (100%)

Table 13

CQOLC Domain 2: Disruptiveness: Item-Specific Summary Statistics

Question #	CQOLC Question	Item Response Frequencies (raw scores)					Mean Response	Total Number of Responses Count (%)
		Count (%)						
		0	1	2	3	4		
Q1	It bothers/bothered me that my daily routine is/was altered.	21 (70%)	5 (16.7%)	2 (6.7%)	1 (3.3%)	1 (3.3%)	.530	30 (100%)
Q3	My daily life is/was imposed upon.	17 (56.7%)	7 (23.3%)	3 (10%)	2 (6.7%)	1 (3.3%)	.770	30 (100%)
Q5	It is/was a challenge to maintain my outside interests.	18 (60%)	6 (20%)	3 (10%)	1 (3.3%)	2 (6.7%)	.770	30 (100%)
Q21	I have/had difficulty dealing with my loved one's changing eating habits.	22 (73.3%)	5 (16.7%)	1 (3.3%)	1 (3.3%)	1 (3.3%)	.467	30 (100%)
Q24	It bothers/bothered me that I need to be available to chauffeur my loved one to appointments.	27 (90%)	1 (3.3%)	0 (0%)	1 (3.3%)	1 (3.3%)	.267	30 (100%)
Q26	The responsibility I have/had for my loved one's care is/was overwhelming.	21 (70%)	3 (10%)	2 (6.7%)	2 (6.7%)	2 (6.7%)	.700	30 (100%)
Q29	It bothers/bothered me that my priorities have changed.	26 (86.7%)	2 (6.7%)	0 (0%)	1 (3.3%)	1 (3.3%)	.300	30 (100%)

Table 14

CQOLC Domain 3: Positive Adaptation: Item-Specific Summary Statistics

Question #	CQOLC Question	Item Response Frequencies (raw scores)					Mean Response	Total Number of Responses Count (%)
		Count (%)						
		0	1	2	3	4		
Q10	I have more of a positive outlook on life since my loved one's illness.	2 (6.7%)	7 (23.3%)	3 (10%)	6 (20%)	12 (40%)	2.633	30 (100%)
Q12	My sense of spirituality has increased.	8 (26.7%)	5 (16.7%)	3 (10%)	7 (23.3%)	7 (23.3%)	2.000	30 (100%)
Q16	I get/received support from my friends and neighbors.	5 (16.7%)	6 (20%)	3 (10%)	8 (26.7%)	8 (26.7%)	2.267	30 (100%)
Q22	I have developed a closer relationship with my loved one.	6 (20%)	4 (13.3%)	5 (16.7%)	5 (16.7%)	10 (33.3%)	2.300	30 (100%)
Q27	I am glad that my focus is on getting my loved one well.	3 (10%)	1 (3.3%)	3 (10%)	7 (23.3%)	16 (53.3%)	3.067	30 (100%)
Q28	Family communication has increased.	6 (20%)	6 (20%)	5 (16.7%)	6 (20%)	7 (23.3%)	2.067	30 (100%)
Q34	I am satisfied with the support I get from my family.	5 (16.7%)	2 (6.7%)	2 (6.7%)	7 (23.3%)	14 (46.7%)	2.767	30 (100%)

Table 15

CQOLC Domain 4: Financial Concerns: Item-Specific Summary Statistics

Question #	CQOLC Question	Item Response Frequencies (raw scores)					Mean Response	Total Number of Responses
		Count (%)						Count (%)
		0	1	2	3	4		
Q6	I am/was under a financial strain.	17 (56.7%)	7 (23.3%)	2 (6.7%)	1 (3.3%)	3 (10%)	.87	30 (100%)
Q7	I am/was concerned about our insurance coverage.	25 (83.3%)	4 (13.3%)	1 (3.3%)	0 (0%)	0 (0%)	.20	30 (100%)
Q8	My economic future is uncertain.	21 (70%)	6 (20%)	1 (3.3%)	2 (6.7%)	0 (0%)	.47	30 (100%)

Table 16

CQOLC Items That Do Not Load Onto Any Particular Domain: Item-Specific Summary Statistics

Question #	CQOLC Question	Item Response Frequencies (raw scores)					Mean Response	Total Number of Responses Count (%)
		Count (%)						
		0	1	2	3	4		
Q2	My sleep is/was less restful.	13 (43.3%)	6 (20%)	5 (16.7%)	5 (16.7%)	1 (3.3%)	1.17000	30 (100%)
Q4	I am/was satisfied with my sex life.	6 (20%)	2 (6.7%)	6 (20%)	10 (33.3%)	6 (20%)	2.27000	30 (100%)
Q13	It bothers/bothered me, limiting my focus to day-to-day.	17 (56.7%)	7 (23.3%)	4 (13.3%)	1 (3.3%)	1 (3.3%)	.73300	30 (100%)
Q15	I feel/felt under increased mental strain.	13 (43.3%)	7 (23.3%)	2 (6.7%)	3 (10%)	5 (16.7%)	1.33300	30 (100%)
Q23	I feel/felt adequately informed about my loved one's illness.	2 (6.7%)	5 (16.7%)	2 (6.7%)	5 (16.7%)	16 (53.3%)	2.93300	30 (100%)
Q30	The need to protect my loved one bothers/bothered me.	24 (80%)	2 (6.7%)	1 (3.3%)	1 (3.3%)	2 (6.7%)	.50000	30 (100%)
Q32	The need to manage my loved one's pain is/was overwhelming.	17 (56.7%)	7 (23.3%)	5 (16.7%)	1 (3.3%)	0 (0%)	.66667	30 (100%)
Q35	It bothers/bothered me that other family members have not shown/did not show interest in taking care of my loved one.	21 (70%)	2 (6.7%)	2 (6.7%)	4 (13.3%)	1 (3.3%)	.73300	30 (100%)

Research Question 3: Relationships of Quality of Life Domains to Demographics

Research Question 3 asked: “Is there any relationship between each of the male partner quality of life domains—Burden, Disruptiveness, Positive Adaptation, and Financial Concerns—and the following for the African American male partners of

African American women with breast cancer: age, marital status, length of relationship with partner (in years), level of education, employment status, religion/faith, stage of breast cancer at diagnosis, and type(s) of breast cancer surgery (ever) received?” The demographic characteristic of type of surgery did not show a level of relationship. Other demographic characteristics are detailed below.

Age. Each of the partner quality of life domains—Burden, Disruptiveness, Positive Adaptation, and Financial Concerns—and age are examined using Spearman-Rank correlations. Bivariate Spearman-Rank correlations between age of male caregiver and each of the following: Burden total score, Disruptiveness total score, Positive Adaptation total score, and Financial Concerns total score are illustrated in Table 17. The findings reflect that the age of male partner and CQOLC Burden total score are significantly, positively correlated ($r = 0.399$, $p\text{-value} = 0.029$). As the age of the partner increases so does the burden total score. The age of the male partner and CQOLC Disruptiveness total score are positively correlated ($r = 0.325$, $p\text{-value} = 0.08$). The age of the male partner and CQOLC Positive Adaptation total score are positively correlated ($r = 0.236$, $p\text{-value} = 0.209$). The age of male partner and CQOLC Financial Concerns total score are positively correlated ($r = 0.347$, $p\text{-value} = 0.06$).

Length of relationship with partner in years. The quality of life domains—Burden, Disruptiveness, Positive Adaptation, and Financial Concerns—and length of relationship with the female partner in years is examined using Bivariate Spearman-Rank correlations between length of a couple’s relationship (in years) and each of the following: Burden total score, Disruptiveness total score, Positive Adaptation total score,

Financial Concerns total score, and CQOLC Total Score. The findings shown in Table 17 reveal the length of couple's relationship (in years) and CQOLC Burden total score are positively correlated ($r = 0.321$, $p\text{-value} = 0.084$). The length of the couple's relationship (in years) and CQOLC Disruptiveness total score are not correlated ($r = 0.080$, $p\text{-value} = 0.675$). The length of couple's relationship (in years) and CQOLC Positive Adaptation total score are not correlated ($r = -0.015$, $p\text{-value} = 0.937$). The length of the couple's relationship (in years) and CQOLC Financial Concerns total score are not correlated ($r = -0.061$, $p\text{-value} = 0.748$).

Educational attainment. The quality of life domains—Burden, Disruptiveness, Positive Adaptation, Financial Concerns—and years of educational attainment of the partner is examined using Bivariate Spearman-Rank correlations to examine each of the following: Burden total score, Disruptiveness total score, Positive Adaptation total score, and Financial Concerns total score. The findings shown in Table 17 reveal the partners' educational attainment in years and CQOLC Burden total score are negatively correlated ($r = -0.342$, $p\text{-value} = 0.064$). The partners' educational attainment in years and CQOLC Disruptiveness total score are negatively correlated ($r = -0.167$, $p\text{-value} = 0.379$). The partners' educational attainment in years and CQOLC Positive Adaptation total score are negatively correlated ($r = -0.347$, $p\text{-value} = 0.061$). The partners' educational attainment in years and CQOLC Financial Concerns total score are not correlated ($r = -0.105$, $p\text{-value} = 0.579$).

Stage of breast cancer at diagnosis. The Bivariate Spearman-Rank correlations between stage of breast cancer at diagnosis and each of the following: burden total score, disruptiveness total score, positive adaptation total score, financial Concerns total score, and CQOLC total Score are found in Table 17. The findings indicate that the stage of breast cancer at diagnosis and CQOLC burden total score are negatively correlated ($r = -0.191$, p -value = 0.312). The stage of breast cancer at diagnosis and CQOLC disruptiveness total score are negatively correlated ($r = -0.222$, p -value = 0.238). The stage of breast cancer at diagnosis and CQOLC positive adaptation total score are positively correlated ($r = 0.175$, p -value = 0.355). The stage of breast cancer at diagnosis and CQOLC financial concerns total score are negatively correlated ($r = -0.335$, p -value = 0.071).

Table 17

Spearman-Rank Correlations

Domain	Man's Age (years)		Length of Relationship (years)		Highest Level of Educational Attainment ¹		Breast Cancer Stage at Time of Diagnosis	
	Correlation Coefficient	p -value	Correlation Coefficient	p -value	Correlation Coefficient	p -value	Correlation Coefficient	p -value
Burden	0.399	0.029	0.321	0.084	-0.342	0.064	-0.191	0.312
Disruptiveness	0.325	0.080	0.080	0.675	-0.167	0.379	-0.222	0.238
Positive Adaptation	0.236	0.209	-0.015	0.937	-0.347	0.061	0.175	0.355
Financial Concerns	0.347	0.060	-0.061	0.748	0.105	0.579	-0.335	0.071
CQOLC Total Score	0.346	0.061	0.218	0.247	-0.325	0.080	-0.168	0.374

Note. Bivariate Spearman-Rank correlations between (1) age of male caregiver (years), (2) length of a couple's relationship (years), (3) highest level of educational attainment, and (4) stage of breast cancer at diagnosis and each of the following: (a) Burden total score, (b) Disruptiveness total score, (c) Positive Adaptation total score, (d) Financial Concerns total score, and (e) CQOLC Total Score.

¹Educational Level categories: < than high school, High school; College; Beyond college (e.g., graduate school, Master's degree, doctoral degree, MD, etc.).

Marital status. For the purpose of data analysis question number 5 of the male partners' demographics questionnaire categories married, never been married, and living with a partner were collapsed into two categories: currently married and not currently married. Kruskal-Wallis One-Way ANOVAs comparing differences in average Burden, Disruptiveness, Positive Adaptation, and Financial Concerns partners' total scores across marital status categories (Tables 18 and 19). Table 18 shows the mean ranks for the scores in four domains by marital status. The values of the test statistic for domains (shown as Chi square) are: 1.15, 1.06, 0.00 and .45. The significance levels indicate no statistically significant differences in the ranks (see Table 19).

Table 18

Kruskal-Wallis One-Way ANOVA Male Partners' Domain-Specific Scores: Marital Status

	Marital Status	N	Mean Rank
CQOLC Burden Total Score 27	Married	27	14.93
	Not currently married	3	20.67
	Total	30	
CQOLC Disruptiveness Total Score	Married	27	14.96
	Not currently married	3	20.33
	Total	30	
CQOLC Positive Adaptation Total Score	Married	27	15.50
	Not Currently married	3	15.50
	Total	30	
CQOLC Financial Concerns Total Score	Married	27	15.17
	Not currently married	3	18.50
	Total	30	

Table 19

Kruskal-Wallis Test Statistics for Marital Status: Male Partners

	CQOLC Burden Total Score	CQOLC Disruptiveness Total Score	CQOLC Positive Adaptation Total Score	CQOLC Financial Concerns Total Score
Chi-Square Test Statistic	1.15	1.06	0.00	.45
Degrees of Freedom	1	1	1	1
Asymptotic Sig. (<i>p</i> -value)	0.23	0.30	1.00	0.50

Religion/Faith. For the purpose of data analysis question number 10 of the male partners' demographics questionnaire categories of religion were collapsed into two categories, Baptist and other. This was done because 53.3% of the population gave Baptist as their faith/religion. Kruskal-Wallis One-Way ANOVA results comparing differences in average Burden, Disruptiveness, Positive Adaptation, and Financial Concerns for partners' total scores across the various categories of self-reported religion/faith are illustrated in Tables 20 and 21. Table 20 shows the mean ranks for the scores in four domains by religion/faith. The values of the test statistic for domains (shown as Chi square) are: 0.69, 0.02, 0.13 and 0.01. The significance levels indicate no statistically significant differences in the ranks (see Table 21).

Table 20

Kruskal-Wallis One-Way ANOVA Male Partners' Domain-Specific Scores: Religion/Faith

	Ranks: Religion	<i>n</i>	Mean Rank
CQOLC Burden Total Score	Baptist	16	14.25
	Other	14	16.93
	Total	30	
CQOLC Disruptiveness Total Score	Baptist	16	15.69
	Other	14	15.29
	Total	30	
CQOLC Positive Adaptation Total Score	Baptist	16	16.03
	Other	14	14.89
	Total	30	
CQOLC Financial Concerns Total Score	Baptist	16	15.34
	Other	14	15.68
	Total	30	

Table 21

Kruskal-Wallis Test Statistics for Religion/Faith: Male Partners

	CQOLC Burden Total Score	CQOLC Disruptiveness Total Score	CQOLC Positive Adaptation Total Score	CQOLC Financial Concerns Total Score
Chi-Square Test Statistic	0.69	0.02	0.13	0.01
Degrees of Freedom	1	1	1	1
Asymptotic Sig. (<i>p</i> -value)	0.41	0.90	0.72	0.91

Employment status. For the purpose of data analysis question number 3 of the male partners' demographics questionnaire categories of employment were collapsed into two categories: currently employed and not currently employed. Kruskal-Wallis One-Way ANOVA was used to compare differences in Burden, Disruptiveness, Positive Adaptation, and Financial Concerns partners' total scores. Tables 22 and 23 provide the

findings. Table 22 shows the mean ranks for the scores in four domains by employment status. The values of the test statistic for domains (shown as Chi square) are: 6.37, 4, 0 and 0.1. The significance levels indicate significant difference in the ranks for Burden total score. The significance levels for the other three domains indicate no statistically significant difference in the ranks (see Table 23).

Table 22

Kruskal-Wallis One-Way ANOVA Male Partners' Domain-Specific Scores: Employment

	Ranks: Employment Status	<i>n</i>	Mean Rank
CQOLC Burden Total Score	Currently Employed	18	18.81
	Not currently employed	12	10.54
	Total	30	
CQOLC Disruptiveness Total Score	Currently Employed	18	18.06
	Not currently employed	12	11.67
	Total	30	
CQOLC Positive Adaptation Total Score	Currently Employed for wages	18	15.58
	Not currently employed	12	15.38
	Total	30	
CQOLC Financial Concerns Total Score	Currently Employed	18	15.89
	Not currently employed	12	14.92
	Total	30	

Table 23

Kruskal-Wallis Test Statistics for Employment Status

	CQOLC Burden Total Score	CQOLC Disruptiveness Total Score	CQOLC Positive Adaptation Total Score	CQOLC Financial Concerns Total Score
Chi-Square Test Statistic	6.37	4	0	0.1
Degrees of Freedom	1	1	1	1
Asymptotic Sig. (<i>p</i> -value)	0.01	0.11	0.95	0.75

Data obtained from conducting descriptive statistics and an independent t -test for the two categories of employment demonstrated that the 18 employed male partners' mean total Burden score was ($M = 13.42$, $SD = 7.05$) and mean total Burden scores for the 12 not currently unemployed male partners was ($M = 6.67$, $SD = 6.07$), $t(28) = 2.71$, $p = .001$. Male partners who were not currently employed had lower mean total Burden scores than those that were currently employed.

Educational attainment. For the purpose of data analysis question number 8 of the male partners' demographics questionnaire categories of education were collapsed into three categories: less than high school/high school, college, and beyond college. Kruskal-Wallis One-Way ANOVA was used to compare differences in Burden, Disruptiveness, Positive Adaptation and Financial Concerns partners' total scores across the partners' categories of highest level of educational attainment. Table 24 shows the mean ranks for the scores in four domains by educational attainment. The values of the test statistic for domains (shown as Chi square) are: 3.50, 0.96, 3.99 and 0.28. The significance levels indicate no statistically significant differences in the ranks (see Table 25).

Table 24

Kruskal-Wallis One-Way ANOVA Male Partners' Domain-Specific Scores: Levels of Educational Attainment

	Ranks: Levels of Education Attained	<i>n</i>	Mean Rank
CQOLC Burden Total Score	<High school, high school	8	11.31
	College	10	14.95
	Beyond college	12	18.75
	Total	30	
CQOLC Disruptiveness Total Score	<High school, high school	8	13.38
	College	10	15.20
	Beyond college	12	17.17
	Total	30	
CQOLC Positive Adaptation Total Score	<High school, high school	8	11.44
	College	10	14.35
	Beyond college	12	19.17
	Total	30	
CQOLC Financial Concerns Total Score	<High school, high school	8	16.81
	College	10	15.00
	Beyond college	12	15.04
	Total	30	

Table 25

Kruskal-Wallis Test Statistics for Levels of Educational Attainment

	CQOLC Burden Total Score	CQOLC Disruptiveness Total Score	CQOLC Positive Adaptation Total Score	CQOLC Financial Concerns Total Score
Chi-Square Test Statistic	3.50	0.96	3.99	0.28
Degrees of Freedom	2	2	2	2
Asymptotic Sig. (<i>p</i> -value)	0.17	0.62	0.14	0.87

Stage of breast cancer at diagnosis. Kruskal-Wallis One-Way ANOVA was used to compare differences in Burden, Disruptiveness, Positive Adaptation, and Financial Concerns of the partners' total scores with the African American women's stage at breast cancer diagnosis. Table 26 shows the mean ranks for the scores in four domains by stage of breast cancer at diagnosis. The values of the test statistic for domains (shown as Chi square) are: 2.41, 2.97, 1.78 and 4.83. The significance levels indicate no statistically significant differences in the ranks (see Table 27).

Table 26

Kruskal-Wallis One-Way ANOVA Male Partners' Domain-Specific Scores: Women's Stage of Breast Cancer at Time of Diagnosis

	<i>Women's Stage of Breast Cancer at Time of Diagnosis</i>	<i>n</i>	Mean Rank
CQOLC Burden Total Score	Stage 0 DCIS	2	19.00
	Stage I	11	13.00
	Stage II	12	15.42
	Stage III	5	19.80
	Total	30	
CQOLC Disruptiveness Total Score	Stage 0 DCIS	2	16.00
	Stage I	11	13.77
	Stage II	12	14.54
	Stage III	5	21.40
	Total	30	
CQOLC Positive Adaptation Total Score	Stage 0 DCIS	2	19.00
	Stage I	11	15.95
	Stage II	12	16.38
	Stage III	5	11.00
	Total	30	
CQOLC Financial Concerns Total Score	Stage 0 DCIS	2	14.75
	Stage I	11	12.86
	Stage II	12	15.13
	Stage III	5	22.50
	Total	30	

Table 27

Kruskal-Wallis Test Statistics for Women's Stage of Breast Cancer at Time of Diagnosis

	CQOLC Burden Total Score	CQOLC Disruptiveness Total Score	CQOLC Positive Adaptation Total Score	CQOLC Financial Concerns Total Score
Chi-Square Test Statistic	2.41	2.97	1.78	4.83
Degrees of Freedom	3	3	3	3
Asymptotic Sig. (<i>p</i> -value)	0.49	0.40	0.62	0.19

Summary

In this study, of the 30 couples who participated, the average age for the African American male partner is 54.87 years, for the African American female it is 58.13 years. The marital status for the couples revealed 88.3% were married with the mean average number of years in the relationship being 22 years. The educational status of the research sample revealed 20% of males and 16% of the females had greater than 16 years of schooling. The full-time employment status of the male partners was 40% and the females was 45.7%. Of the males, 37.9% had private insurance, 41.4% of the females had private insurance. The median annual total household income was \$80,000 for females, \$77,628 for the males. Fifty percent of the couples had at least one child under the age of 18 residing in the household, although the reported average number of people in the household was two. Sixty-five percent of the couples reported that others living in the household contributed to the household income.

The African American women's cancer-related statistics revealed 13.3% were diagnosed in 2008 and 13.3% were diagnosed in 2011. Stage II breast cancer diagnosis had the most women being diagnosed (40%). Thirty percent of the women had

mastectomies, 56% had lumpectomies, and 13.3% had both. Fifty percent of the women had both radiation and chemotherapy, 30% had chemotherapy only, 6.67% had radiation therapy only, and 3.33% had hormone therapy (HT) only. No sample participants reported having had chemotherapy, radiation, and HT.

The male partners' Caregiver Quality of Life questionnaire scores showed the average quality of life score as 74.8 out of a maximum score of 140. The domain-specific scores were: mean Burden total score 29.2, mean Disruptiveness total score 24.2, mean Positive Adaptation total score 10.9, and mean Financial Concerns total score 10.4.

Bivariate Spearman-Rank correlations between the age of the male partner and each of the following: Burden total score, Disruptiveness total score, Positive Adaptation total score, and Financial Concerns total scores were computed. The findings were that the age of the male partner and CQOLC Burden total score ($p = 0.029$) is statistically significantly, positively correlated. No other domains specific to categories were realized. Kruskal-Wallis One-Way ANOVAs comparing differences in average Burden, Disruptiveness, Positive Adaptation, and Financial Concerns partners' total scores with marital status, religion, employment status, highest level of educational attainment and African American women's stage at breast cancer diagnosis were computed. The findings were that the average male partner's CQOLC Burden total score ($p = 0.01$) differs significantly by employment status. Data from descriptive statistics and independent t -tests demonstrated not currently employed male partners having a lower mean total Burden score.

5. CONCLUSIONS

This chapter provides the summary, discussion, limitations, and implications for nursing of this research study. African American women have the highest incidence of morbidity and mortality from breast cancer in comparison to other ethnicities (Gwyn et al., 2004; Hunter, 2000; Joslyn & West, 2000). According to the American Cancer Society (ACS) (2013), breast cancer is the most common cancer among African American women and one of the leading causes of death in this population.

The adverse effects of this disease and treatment will disrupt, cause distress for, and impact not only the quality of life of the African American woman, but may extend to and negatively impact the quality of life of her male partner. The partner's quality of life is important for the woman as it contributes to the positive progression and prognosis for her breast cancer diagnosis. Spouses have been found to play a crucial role in the woman's ability to respond to and cope with the stress of living with breast cancer (Borwell, 1996; Northouse, 1989). Lichtman, Taylor, and Wood (1987) found that positive relationships existed between spousal support and reduced psychological distress among women with breast cancer. According to Cutrona and Russell (1990), spousal support may enhance the ability of those who are ill to cope more effectively with their disease, understand better the threatening event they face, increase motivation to take action, and reduce emotional distress.

While the quality of life of partners of women with breast cancer has been investigated in other racial/ethnic populations (Baider & De-Nour, 1988; Bergelt et al., 2008; Wagner et al., 2005), heretofore data regarding the quality of life of the partner of the African American woman with breast cancer had to be gleaned from research studies that included small numbers of African Americans. Therefore, this current study explored the impact of breast cancer on the self-reported quality of life of the partners of African American women with breast cancer.

This study was guided by the following research questions:

1. What are the demographic characteristics of African American women with breast cancer and their partners?
2. What is the level of self-reported quality of life in the partners of African American women with breast cancer?
3. Is there any relationship between the quality of life domains—disruptiveness, burden, financial concerns, and positive adaptation—of the partners of African American women with breast cancer and the following?
 - a. Age
 - b. Years of education
 - c. Employment status
 - d. Marital status
 - e. Length of time with partner
 - f. Stage at breast cancer diagnosis
 - g. Type of surgery

h. Faith

The conceptual framework of the study was a modified version of the Sprangers and Schwartz (1999) model of response shift and quality of life. The factors used were defined as catalysts, which are health states, changes in health states, other health-related events, the experience of such events, and other events that may affect and have an impact on the quality of life. For the purpose of this study the African American woman's diagnosis of breast cancer was the catalyst. Antecedents were the characteristics of the person and environments that may have influenced the type of catalysts and mechanisms of appraisal. The mechanisms of appraisal included the behavioral, cognitive, or affective processes that accommodate changes in catalysts, such as initiating social comparisons or reordering goals. Both were examined using the male partners' sociodemographic information.

The perceived quality of life was addressed using the Caregiver Quality of Life Index-Cancer (CQOLC) questionnaire. The questionnaire used four domains: Burden, Disruptiveness, Financial Concerns, and Positive Adaptation. This research utilized the conceptual definitions as the operational definitions.

The literature review synthesized research on the domains of quality of life of partners of cancer patients. The review revealed a dearth of research on the quality of life of the spouses/partners of breast cancer patients of specific racial/ethnic groups. The particularly limited amount of research on the quality of life of partners of African American women with breast cancer supported the need to conduct this study.

Total and Domain-Specific Caregiver Quality of Life Scores

This research study's results are expected to fill a void of missing literature on the impact of breast cancer on the quality of life of African American women's partners. First, what is the level of self-reported quality of life in the partners of African American women with breast cancer? The answer for this sample ($n = 30$) was provided by the results of the Caregiver Quality of Life Index-Cancer questionnaire's total scores. The partners' mean Caregiver Quality of Life index score was 74.8 with a standard deviation of ± 15.55 ; the minimum possible score was 0 and the maximum possible score was 140. This study's male partners' overall low quality of life scores are consistent with a study conducted by Wagner et al. (2005) in which the Medical Outcomes Study SF-36 was used to obtain quality of life scores of 30 spouses of women with breast cancer and the quality of life scores of 30 spouses of women who had no acute or chronic illness. The study reported lower quality of life scores among husbands of women with breast cancer than the comparison husbands. Turkoglu and Kihc (2012) conducted a study of 190 Turkish caregivers of cancer patients to examine the effects of burden on their quality of life using the Caregiver Quality of Life Index-Cancer instrument. In their study the total Caregiver Quality of Life Index score was 81.4. The total Caregiver Quality of Life Index score for other similar studies was 80.1 (Tang, 2009) and 71.77 (Bektas & Ozer, 2009). These scores are slightly higher than the total Caregiver Quality of Life Index score of this current study, although still low when considering the maximum possible score of 140.

Burden

The CQOLC total quality of life scores encompass scores derived from four domains: Burden, Disruptiveness, Positive Adaptation, and Financial Concerns. The first domain, Burden, can also be referred to as strain or role strain. The terms are often used interchangeably to refer to the physical, psychological, social, and/or financial reactions that can be experienced in caregiving (Given et al., 1992; Zarit, Todd, & Zarit, 1986).

The term burden reflects a negative approach toward the caregiving experience. However, some studies report the beneficial effects of caregiving (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989). The experiences of caregiving can be positive in terms of love, affection, rewards, challenges, meaning, purpose in life, and/or joyful events (Oberst et al., 1985). Caregiving may increase the caregivers' feelings of pride in their ability to meet challenges and improve their sense of self-worth (Motenko, 1989). Folkman, Chesney, and Christopher-Richards (1995) reported that caregiving may improve the quality of relationships between caregivers and care recipients, which may contribute to increased self-esteem for both individuals.

Studies have identified factors such as the partners' health prior to a care situation (Stommel, Given, & Given, 1990), as well as sociodemographic and socioeconomic status, which should be considered when evaluating caregiver burden. However, it must be noted that George and Gwyther (1986) and Biegel, Milligan, Putham, and Song (1994) did not find any relationship between socioeconomic characteristics and caregiver burden.

Regarding the partners' health status, this study's partners' responses to question 12 of the demographics questionnaire, "Do you have health problems that affect your ability to help care for your wife/partner?" revealed 86.7% of the male partners responded "no." Thus the majority percentage in this sample population reflected no health-related barriers to the partners' ability to assist with providing care.

Caregiver burden is often used to describe multiple dimensions of distress that result from an imbalance between care demands and the availability of resources to meet those demands.

Findings of a 2004 research study (Grunfield et al.) of 89 male caregivers of whom 53% were 55 years or older of women with advanced breast cancer revealed they had a high level of perceived burden. Burden was found to be the most important predictor of both anxiety and depression. This explanation may provide an understanding as to the Spearman- rank Correlation of partners' Burden score and partners' age in this current study. This domain and category were significant.

Disruptiveness

A person's stock of knowledge of self and the social world is disrupted by the illness experience (Bury, 1982). An illness, such as breast cancer, can cause a major kind of disruptive experience on the lives of patients and their families. Aspects of this disruptiveness can modify the behaviors, roles, and responsibilities held by the woman with breast cancer and her partner in the family unit (Northouse, 1989). There is also the potential for disruptiveness caused by the financial, medical, and cultural aspects of the disease. The disruptive symptoms of the illness; its impact on the everyday life at home

and at work, including giving time to manage the symptoms of the illness; medical treatments; and costs associated with the illness can negatively impact the quality of life of the woman with breast cancer and her partner. The partners' Disruptiveness scores were obtained to examine this factor. The average Disruptiveness total CQOLC score for the male partners was 24.2 ± 4.89 (mean \pm SD) out of a maximum score of 28 and minimal score of 0.

Similar findings are revealed in a quantitative descriptive study of 20 husbands of Israeli women with breast cancer. Eleven of the husbands in the study reported that they were successful in "rising above the problems incurred due to their wives' illness" (Woloski-Wruble & Kadmon, 2002). Morgan et al. (2005), in an exploratory qualitative study of African American couples coping with breast cancer, revealed that several couples expressed that previous life stressors had prepared them for the breast cancer diagnosis. A study conducted by Dorval et al. (2005) of 282 women with breast cancer and their partners revealed that 42% of the sample reported that the breast cancer experience had brought them closer together.

This research study's theoretical model of response shift and quality of life may assist in gaining an understanding as to the domain-specific scores of Disruptiveness. The antecedents, *sociodemographics* and mechanisms, *faith/religion*, are important components in the partners' self-reported quality of life in this study. The study's partners' characteristics of being well-educated, affluent and perhaps having experienced some of life's challenges may explain this domain scores.

Positive Adaptation

The Positive Adaptation domain score revealed the lowest total score of the four domains. In an effort to understand this low score, it is important to understand adaptation. *Adaptation* in the partner means to change the family structure, role relationships, and relationship rules when a stressor occurs—in this case the breast cancer diagnosis of the African American woman. It is an indicator of the partner's adjustment to the marriage during and after the breast cancer experience. Adaptation refers to the flexibility of the partner and his ability to change the power structure and relationship roles in the face of a situational stressor (Carter & Carter, 1993).

There is conflicting research about the duration of the adaptation process to breast cancer. Hannum, Giese-Davis, Harding, and Hatfield (1991) suggested that the cancer crisis resolves 1 year after surgery. Baider and De-Nour (1988) and Northouse (1988) maintained that adjustment to cancer is a longer-term process with partner emotional effects apparent 2 to 3 years following surgery. In a study conducted by Northouse (1988) of 50 women with breast cancer and their husbands at 3 and 30 days post mastectomy, the men's psychosocial adjustment was not related to age, education, length of marriage, or degree of severity of their wives' medical condition. Rather, the husband's psychosocial adjustment was related to men who had a positive outlook. Thus this may be the rationale for the low Positive Adaptation scores of the partners in this study.

Financial Concerns

Breast cancer and its treatment are expensive. In a summary of analyzed literature Campbell and Ramsey (2009) reported the lifetime per patient cost of breast cancer in the United States ranged from \$20,000 to \$100,000. A study conducted by Grunfeld et al. (2004) of 89 caregivers of women with breast cancer found prescription drugs the most significant burden. The average financial burden during the patient's illness was higher for those without extended health insurance, with the average cost \$8,292.00. These findings are not congruent with this study's findings as the average financial concerns total CQOLC score for the male partners of this sample was 10.47 ± 2.1 (mean \pm SD). The financial concerns domain percentages for answers of "not at all," that is, not a concern at all, to questions 6, 7, and 8 were significant at 56%, 83%, and 70%. This is not surprising as the median total household income for this research study's population was \$80,000 for women and \$77,628 for men; 37.9% of the men and 41.4% of the women had private insurance.

Relationship of Variables to Total Domain Scores

Of the eight variables examined in this study, the results for the variables (a) average age of partners, (b) length of time with partner, and (c) stage of breast cancer at diagnosis of this sample would lead one to think a relationship would exist with the four total domain scores. However, further analysis pointed only to the age of the partner and employment status as related variables.

Age of Partner

In an effort to assess for a correlation between the variables, the non-parametric Bivariate Spearman-Rank Correlation statistical test was used with each of the individual ranked/ordinal variables. The age of the male partner, length of the couple's relationship in years, and stage of breast cancer at diagnosis were used to check for correlation with each of the following: Burden total score, Disruptiveness total score, Positive Adaptation total score, Financial Concerns total score, and CQOLC total score. All correlations except one were not significant at the 95% significance level. That finding for the age of the male partner and CQOLC burden total score were significantly, positively correlated at the 95% significance level.

This was an interesting result as age as a predictor of burden and adjustment following breast cancer in the literature revealed various findings. Spousal age has been studied as a possible predictor of distress. According to Sales, Schulz, and Biegel (1992), younger spouses react more emotionally than older ones to the partner's illness, but older partners may need more physical and administrative services. Wellisch et al. (1978) found that younger partners and couples under 50 experience more emotional distress than do older partners. This finding may be related to the different challenges facing partners based on their age, with older partners struggling with practical tasks and younger spouses managing the emotional reactions of anger and resentment at the disruption that breast cancer has created. However, this is challenged as studies such as that by Baider and De-Nour (1988) show no effect for age.

Faith/Religion

In the examination of the quality of life of partners of African American women with breast cancer, the literature review indicated it would be important to review the theoretical concept of faith/religion as a mechanism in the partners' self-reported perceived quality of life. For the purpose of this study, faith/religion included the behavioral, cognitive, or affective processes that accommodate changes in catalysts such as initiating social comparisons or reordering goals.

Faith and religion play an important role in the lives of African Americans. It is well documented that this population reports higher levels of involvement than other ethnicities. A qualitative study of 60 African American and White caregivers and patients was conducted to examine the importance of spirituality in caregiving and care receiving. The findings revealed more African Americans than White caregivers described spirituality as all encompassing (Theis, Biordi, Coeling, Nalepka, & Miller, 2003).

Both religious and nonreligious people make religious attributions and engage in religious practices such as prayer to cope with adversity (Park & Cohen, 1993). Greater use of positive religious coping strategies is associated with higher self-esteem, sense of control, comfort, better quality of life, psychological adjustment, and spiritual and stress-related growth (Pargament, Smith, Koenig, & Perez, 1998). Serious illness such as cancer is an event that can bring to the forefront an individual's faith and religious involvement. This research study's population's findings mirror this in that the majority of the male partners reported a religious affiliation and acknowledged that their faith/religion had been a great deal of help with their partners' breast cancer experience.

Other Variables

Kruskal-Wallis One-Way ANOVA was used to compare differences in Burden, Disruptiveness, Positive Adaptation, and Financial Concerns total scores across categories of highest level of educational attainment for the male partners. The findings reflect that none of the average domain-specific total scores significantly differ by the male partner's level of educational attainment at the 95% significance level. Kruskal-Wallis One-Way ANOVA comparing differences in Average Burden, Disruptiveness, Positive Adaptation, and Financial Concerns total scores across the various categories of self-reported Religion/Faith for male partners' findings revealed that none of the average domain-specific total scores differ. Kruskal-Wallis One-Way ANOVA comparing differences in average Burden, Disruptiveness, Positive Adaptation, and Financial Concerns total scores across employment status categories for the male partners was conducted. The findings revealed significant findings with Burden and employment status.

In an effort to understand burden to employment status a look is given as to how breast cancer imposes substantial burdens on caregiving and the financial burden that is associated with the onset and treatment of the disease.

Cancer frequently follows an unpredictable course, with patients experiencing numerous disruptions in their lives. The enormous financial burden that accompanies the onset and subsequent treatment of cancer become even more overwhelming.

It is estimated that the United States lifetime per patient costs of breast cancer range from \$20,000 to \$100,000 (Campbell & Ramsey, 2009). Much of this cost reflects

hospital stays, physician visits, and chemotherapeutic agents which may be fully or partially covered by insurance. There are out-of-pocket costs and copayments that are not reimbursed or partially reimbursed by third party payers. Such costs can impose devastating financial burdens on the patient and her partner (Emanuel et al., 2000). These factors would impact the partner that is currently employed and/or who has a fixed income and significantly impact the currently unemployed partner.

There is evidence demonstrating the negative effects of caregiver burden particularly in the areas of psychological well-being and quality of life of family caregivers of patients with cancer. (Sherwood et al., 2005). As such it is possible that measures of burden may be associated with caregiver employment (Sherwood et al. 2008).

Given et al. (2004) conducted a prospective longitudinal study of 152 caregivers of cancer patients to examine variables that predicted caregiver burden and depression in caregivers. Caregivers aged 45-54 reported the highest levels of depressive symptoms. Spouses with lower levels of depressive symptoms were more likely to be employed. Employed spouses reported lower levels of depressive symptoms than those spouses who were unemployed. This finding suggests that employment outside the home may act as a buffer to or as respite from the caregiver experience. However, employment may lead to an overall level of psychological distress because of the ways that caregivers negotiate caregiving and employment, including withdrawal or absence from work and/or reduction in work productivity (Given et al., 2004). Many employed caregivers are confronted with dual roles of employment as caregiving can be a full-time job itself. This

can lead to work-related issues like missed days, low productivity, and work interruptions. Some caregivers may need to take unpaid leave, turn down promotions, or lose work benefits. Caregivers in specific types of jobs (temps, freelancers, consultants, entrepreneurs), may face increased difficulties because if they do not work there is no pay (Neal, Ingersoll-Dayton, & Starrels, 1997).

The few studies that have addressed racial and ethnic differences among caregivers generally have not focused specifically on working caregivers. One exception is a study by Lechner (1993), which found that African-American caregivers reported less support from supervisors and less flexible policies regarding family concerns than White caregivers. However, this study reported that work interferences affected Whites' emotional well-being and African Americans' physical well-being. The researcher attributed this difference to Blacks receiving less adequate health care. Other studies report this variance, better emotional adjustment of African American caregivers, to cultural mechanisms (Farrah et al., 1997, White, Townsend, & Stephens, 2000). The important factor and similarity is that both groups were adversely affected.

An important statistical finding in this study was the partners' self-reported mean total CQOLC score of 74.8 out of a maximum possible score of 140. This score provides a quantitative answer to the question, "What is the level of the self-reported quality of life of the male partners of African American women with breast cancer?"

Limitations and Suggestions for Further Research

The participants in this study were highly educated, older, and affluent. Although there is a need for research on middle- and upper-income African Americans, these

factors and the small sample size limit the ability to generalize this study's results to all partners of African American women with breast cancer. Additionally, potential bias may exist as participants responded once to the questionnaires. Additional responses and questioning may have revealed further insight about the participants and their experiences.

A literature search used to derive a multifaceted approach to recruiting African American couples. Although culturally informed approaches were used based upon literature describing barriers to research participation for African Americans that were built on successful strategies, revisiting the strategies used for recruitment is needed in order to know which aspect would have been most effective in increasing the sample size.

In spite of these limitations, the present study contributes significant information about the male partners of African American women with breast cancer which, to this researcher's knowledge, did not heretofore exist. Additionally, rich data was collected from the African American women with breast cancer, such as the time of diagnosis, stage, and treatment for the breast cancer. This information could provide added information for the African American couples' breast cancer experience.

Implications for Nursing

The literature suggests that partners of individuals with cancer receive little attention from, information from, and communicate infrequently with healthcare professionals (Kalayjian, 1989; Meissner, Anderson, & Odenkirchen, 1990; Northouse, 1988). Rees and Bath (2000) found that most spouses who accompany their wives to

physician visits sought information from various sources, but they mostly relied on breast care nurses for information. Several researchers have reported that the information needs of partners and family members of individuals with cancer are frequently overlooked (Kalayjian, 1989; Meissner et al., 1990; Stedeford, 1981). Bond (1982) found that the relatives of cancer patients found it difficult to approach doctors. Many men may also be uncomfortable with medical staff. In a research study of 50 mastectomy patients and their husbands, Northouse (1988) found that husbands reported less support from health professionals than their wives throughout the breast cancer illness.

Northouse and Peters-Golden (1993) conducted a review of the literature which suggested that the spouses of individuals with cancer need information about the types of cancer, the treatment options, and the side effects of treatments. Northouse and Peters-Golden found that the spouses of women with breast cancer indicated that information helped them cope with the breast cancer experience. Lewis (1990) reflected that partners of individuals with cancer need verbal information from healthcare professionals and need opportunities to ask healthcare professionals questions. Petrie et al. (2001) conducted a literature review including 16 studies which examined the support care needs of spouses of women with breast cancer. The needs were divided into emotional, psychological, informational, spiritual, physical, and practical needs. Findings of the review revealed that minimal research had been conducted regarding the responses of spouses to their wives', and that healthcare professionals rarely addressed the supportive care needs of spouses of women with breast cancer. Petrie et al. recommended that healthcare professionals develop programs and interventions that would provide

supportive care for the spouses and that longitudinal studies should be conducted to assess spouses' adjustment over time to determine how to increase professional contact with the spouses.

A research study conducted by Kadmon et al. (2008) of 50 Chinese and Israeli husbands of women with breast cancer showed that culture had an impact on spousal responses to the wife's illness. The researchers recommended developing culturally sensitive breast cancer nursing care.

Healthcare professionals can help the partners of African American women with breast cancer by being sensitive to their needs, inquiring about their and their partners' needs, providing culturally sensitive information, asking if they have questions, and referring them to other African American men who have been or may be going through the experience. Partners may require various types of assistance to cope with their partners' breast cancer journey.

Baider stated "The family in general and the spouse in particular, cannot be looked on as natural supporters for cancer patients, but rather as a system that is itself in need of help and support" (1995, p. 239).

This study concluded that the quality of life of male partners of African American women with breast cancer is negatively impacted by the breast cancer experience. The findings support the need for nurses and all healthcare providers to provide ongoing communication to patients' partners and families by developing culturally sensitive, age-specific education, support, and interventions that will assist male caregivers in balancing

employment and care demands in an effort to improve the quality of life of the African American woman with breast cancer, her male partner, and family.

APPENDIX A. DEMOGRAPHICS QUESTIONNAIRE FOR AFRICAN AMERICAN WOMEN WITH BREAST CANCER

1. What is your age? ____
2. What is your race? ____
3. Are you currently?
 - a. employed for wages ____
 - b. self-employed ____
 - c. unemployed ____
 - d. unable to work ____
 - e. retired ____
4. Has there been a change in your employment since your breast cancer illness?

____ Yes ____ No
5. Are you currently?
 - a. married ____
 - b. never been married ____
 - c. living with a partner ____
6. Were you previously divorced, separated or living apart from your partner prior
to your breast cancer diagnosis? ____ Yes ____ No
7. How long have you been with your husband/partner? Months ____ Years ____
8. What is the highest number of years of school you completed? ____

did not attend school ____
9. Do you have health insurance? ____ No ____ Yes

If yes, what type? ____ Private Insurance ____ Medicare ____ Medicaid
10. What is your faith/religion if any? _____
11. Has your faith or religion assisted you in coping with your breast?
cancer experience?

Yes ____
No ____

If yes, to what degree?

A great deal _____

Some help _____

Not much help _____

Not applicable _____

12. When were you diagnosed with breast cancer? _____

13. Please check the cancer stage at diagnosis.

Stage I _____

Stage II _____

Stage III _____

Stage IV _____

14. Did you have chemotherapy?

Yes _____

No _____

15. If yes, how long ago?

Months _____ Years _____

16. Did you have radiation?

Yes _____

No _____

17. If yes, how long ago?

Months _____ Years _____

18. Did you have hormone therapy?

Yes _____

No _____

19. If yes, how long ago?

Months _____ Years _____

20. Did you have a?

Mastectomy _____

Lumpectomy _____

Both _____

No surgery _____

21. Do/did you need help with your activities of daily living after surgery, during chemo therapy or radiation therapy? No ___ Yes ___

If yes, how many Minutes ___ Hours a day? ___

22. Including yourself, how many people live in your household? _____

23. If others live in the household, do they contribute to the household income? __ Yes__ No
24. Are there any children in your household under the age of 18?
Yes ____ If yes, how many ____ No ____
25. What is your {combined} annual household income? _____

**APPENDIX B. DEMOGRAPHICS QUESTIONNAIRE FOR THE
HUSBANDS/PARTNERS OF AFRICAN AMERICAN WOMEN WITH BREAST
CANCER**

1. What is your age? ____
2. What is your race? _____
3. Are you currently?
 - a. employed for wages ____
 - b. self-employed ____
 - c. unemployed ____
 - d. unable to work ____
 - e. retired ____
4. Has there been a change in your employment since your partner's breast cancer illness? ____ Yes ____ No
5. Are you currently?
 - a. married ____
 - b. never been married ____
 - c. living with a partner ____
6. Were you previously divorced, separated or living apart from your partner prior to her breast cancer diagnosis? ____ Yes ____ No
7. How long have you been with your wife/partner? Months ____ Years ____
8. What is the highest number of years of school you completed? ____
did not attend school ____
9. Do you have health insurance? ____ No ____ Yes
If yes, what type? ____ Private Insurance ____ Medicare ____ Medicaid
10. What is your faith/religion if any? _____

11. Has your faith or religion assisted you in coping with your wife's/partner's breast cancer experience?

☐ No

☐ Yes

If yes, to what degree?

A great deal of help ☐

Some help ☐

Not much help ☐

Not applicable ☐

12. Did/does your partner/wife need help with her activities of daily living after chemo therapy or radiation therapy? ☐ No ☐ Yes

If yes, how many Minutes ☐ Hours a day? ☐

13. Do you have any health problems that affect your ability to give health care?

☐ No ☐ Yes

If yes, please explain _____

14. Are there any children in your household under the age 18?

☐ Yes If yes, how many? ☐ What are their ages? ☐ No ☐

15. Including yourself, how many people live in your household? ☐

16. If others live in the household, do they contribute to the household income?

☐ Yes ☐ No

17. What is your {combined} annual household income? ☐

APPENDIX C. CAREGIVER QUALITY OF LIFE INDEX-CANCER SCALE (CQOLC)

ID#: _____ DATE: ____/____/____

CAREGIVER QUALITY OF LIFE INDEX-CANCER

Below is a list of statements that other people caring for loved ones with cancer have said are important. By circling one number per line, please indicate how true each statement has been for you during the past 7 days.

0 = Not at all **1**= Somewhat **2**= A little bit **3** = Quite a bit **4** = Very much

During the past 7 days:

- | | |
|--|-----------|
| 1. It bothers me that my daily routine is altered. | 0 1 2 3 4 |
| 2. My sleep is less restful. | 0 1 2 3 4 |
| 3. My daily life is imposed upon. | 0 1 2 3 4 |
| 4. I am satisfied with my sex life. | 0 1 2 3 4 |
| 5. It is a challenge to maintain my outside interests. | 0 1 2 3 4 |
| 6. I am under a financial strain. | 0 1 2 3 4 |
| 7. I am concerned about our insurance coverage. | 0 1 2 3 4 |
| 8. My economic future is uncertain. | 0 1 2 3 4 |
| 9. I fear my loved one will die. | 0 1 2 3 4 |
| 10. I have more of a positive outlook on life since
my loved one's illness. | 0 1 2 3 4 |
| 11. My level of stress and worries has increased. | 0 1 2 3 4 |
| 12. My sense of spirituality has increased. | 0 1 2 3 4 |
| 13. It bothers me, limiting my focus to day-to-day. | 0 1 2 3 4 |
| 14. I feel sad. | 0 1 2 3 4 |
| 15. I feel under increased mental strain. | 0 1 2 3 4 |
| 16. I get support from my friends and neighbors. | 0 1 2 3 4 |
| 17. I feel guilty. | 0 1 2 3 4 |
| 18. I feel frustrated. | 0 1 2 3 4 |
| 19. I feel nervous. | 0 1 2 3 4 |
| 20. I worry about the impact my loved one's illness
has had on my children or other family members. | 0 1 2 3 4 |
| 21. I have difficulty dealing with my loved one's
changing eating habits. | 0 1 2 3 4 |

- | | |
|---|-----------|
| 22. I have developed a closer relationship with my loved one. | 0 1 2 3 4 |
| 23. I feel adequately informed about my loved one's illness. | 0 1 2 3 4 |
| 24. It bothers me that I need to be available to chauffeur my loved one to appointments. | 0 1 2 3 4 |
| 25. I fear the adverse effects of treatment on my loved one. | 0 1 2 3 4 |
| 26. The responsibility I have for my loved one's care at home is overwhelming. | 0 1 2 3 4 |
| 27. I am glad that my focus is on getting my loved one well. | 0 1 2 3 4 |
| 28. Family communication has increased. | 0 1 2 3 4 |
| 29. It bothers me that my priorities have changed. | 0 1 2 3 4 |
| 30. The need to protect my loved one bothers me. | 0 1 2 3 4 |
| 31. It upsets me to see my loved one deteriorate. | 0 1 2 3 4 |
| 32. The need to manage my loved one's pain is overwhelming. | 0 1 2 3 4 |
| 33. I am discouraged about the future. | 0 1 2 3 4 |
| 34. I am satisfied with the support I get from my family. | 0 1 2 3 4 |
| 35. It bothers me that other family members have not shown interest in taking care of my loved one. | 0 1 2 3 4 |

APPENDIX D. SCORE SHEET FOR FAMILY CAREGIVER QOL SCALE

Item Number Reverse? Item Response Item Score

1 4 -	_____	=	_____
2 4 -	_____	=	_____
3 4 -	_____	=	_____
4 0 -	_____	=	_____
5 4 -	_____	=	_____
6 4 -	_____	=	_____
7 4 -	_____	=	_____
8 4 -	_____	=	_____
9 4 -	_____	=	_____
10 0 -	_____	=	_____
11 4 -	_____	=	_____
12 0 -	_____	=	_____
13 4 -	_____	=	_____
14 4 -	_____	=	_____
15 4 -	_____	=	_____
16 0 -	_____	=	_____
17 4 -	_____	=	_____
18 4 -	_____	=	_____
19 4 -	_____	=	_____
20 4 -	_____	=	_____
21 4 -	_____	=	_____
22 0 -	_____	=	_____
23 0 -	_____	=	_____
24 4 -	_____	=	_____
25 4 -	_____	=	_____
26 4 -	_____	=	_____
27 0 -	_____	=	_____
28 0 -	_____	=	_____
29 4 -	_____	=	_____
30 4 -	_____	=	_____
31 4 -	_____	=	_____
32 4 -	_____	=	_____
33 4 -	_____	=	_____
34 0 -	_____	=	_____

35 4 - _____ = _____
Sum ITEM SCORES [_____] x 35 : [_____] = [_____]
Enter number of items answered _____

APPENDIX E. CAREGIVER QUALITY OF LIFE INDEX-CANCER SCALE (CQOLC) FACTORS AND SCORING

FACTORS OF THE CQOLC

BURDEN	10 items: #9, 11, 14, 17, 18, 19, 20, 25, 31, 33
DISRUPTIVENESS	7 items: #1, 3, 5, 21, 24, 26, 29
POSITIVE ADAPATATION	7 items: #10, 12, 16, 22, 27, 28, 34
FINANCIAL CONCERNS	3 items: #6, 7, 8

SCORING PROCEDURES FOR CQOLC

Reverse code appropriate items according to attached SCORE SHEET.

Individual CQOLC factor scores obtained by summing the responses to the items that load on that particular factor.

Total CQOLC score obtained by summing scores for all 35 items.

Note: Not all 35 items load on a factor; items 2, 4, 13, 15, 23, 30, and 32 do not load on any factor, but are included in total CQOLC score.

RELIABILITY: INTERNAL CONSISTENCY

ALPHA COEFFICIENT

CQOLC TOTAL	.90
BURDEN	.89
DISRUPTIVENESS	.83
POSITIVE ADAPTATION	.73
FINANCIAL CONCERNS	.81

RELIABILITY: TEST-RETEST COEFFICIENTS (administrations 2 weeks apart)

CORRELATION COEFFICIENT

CQOLC TOTAL	.94
BURDEN	.90
DISRUPTIVENESS	.91
POSITIVE ADAPTATION	.82
FINANCIAL CONCERNS	.91

APPENDIX F. RESPONSES OF THREE CONTENT VALIDITY ANALYSTS

The Caregiver Quality of Life Cancer Scale

This instrument will be used in a proposed study for a sample of partners of African American women with breast cancer to assess their self reported quality of life.

Please select on a 1 – 5 scale with 5 being the highest number how you would rate this instrument.

- | | |
|---|--------------|
| 1. Is this instrument appropriate for this ethnic group? | _____5_____ |
| 2. Are the questions clear? | _____5_____ |
| 3. Does the instrument measure what it is intended to measure? | _____4_____ |
| 4. Are there questions which should be deleted? If yes, which one/s? | _____no_____ |
| 5. Are there questions which should be added? If yes, please provide below. | _____no_____ |

Other comments:

1. I don't see anything in the questions that would not be appropriate for this ethnic group. However, this is ultimately an empirical question, which would be addressed by giving the scale to various ethnic groups and looking for differences in response patterns. Since you can't do that, this is probably as good a scale as you can find.
2. The questions (statements, really) are short and clear, and do not seem to present any obvious difficulties for comprehension.
3. The instrument "appears" to measure the named components (i.e., Burden, Disruptiveness, etc.), although the nature of the Burden component is not particularly clear. That is, it's not clear how a statement like, "I fear my loved one will die" reflects a burden. Perhaps the authors of the scale give a rationale for their factor naming. For the other factors, however, the titles seem to relate clearly to the content of the statements. Overall, the scale seems to have content validity. But, I cannot determine if it has construct validity (that is, does it truly measure what it is intended to measure).
4. You should not delete questions from a standardized scale without clear justification, since you lose the benefit of prior research.
5. Same comment as #4, with respect to adding questions – don't do it.

Thank you for your participation!

The Caregiver Quality of Life Cancer Scale

This instrument will be used in a proposed study for a sample of partners of African American women with breast cancer to assess their self reported quality of life.

Please select on a 1 – 5 scale with 5 being the highest number how you would rate this instrument.

- | | |
|---|--------------|
| 1. Is this instrument appropriate for this ethnic group? | __5__ |
| 2. Are the questions clear? | __5__ |
| 3. Does the instrument measure what it is intended to measure? | see comments |
| 4. Are there questions which should be deleted? If yes, which one/s? | see comments |
| 5. Are there questions which should be added? If yes, please provide below. | |

Other comments:

Question 1: I saw no questions that I thought were specific to an ethnic group. However, I assume you intend to pilot test with the target ethnic group and compare your results with those published by the author of CQOLC.

Question 3: This question is another way of asking is the instrument valid. In general, validity concerns whether the concepts being studied are actually the ones being measured or tested. It is impossible to tell if the CQOLC is valid by reading it. I recommend checking with the developer of this instrument about how it was validated.

Based on data in the attachment, it looks like your instrument is reliable. You provided the data for two often used indicators of a scale's reliability: test-retest reliability and internal consistency. Some authors recommend that you change the item numbers on the test when you retest.

Question 4: If you have questions that don't load on a factor, why use them?

Question 5: Since I am not an expert in the subject area, I don't know if there are questions that should be added.

Thank you for your participation!

The Caregiver Quality of Life Cancer Scale

This instrument will be used in a proposed study for a sample of partners of African American women with breast cancer to assess their self reported quality of life.

Please select on a 1 – 5 scale with 5 being the highest number how you would rate this instrument.

1. Is this instrument appropriate for this ethnic group? *5
2. Are the questions clear? 5
3. Does the instrument measure what it is intended to measure? 5
4. Are there questions which should be deleted? If yes, which one/s? *yes
5. Are there questions which should be added? If yes, please provide below.*yes

Other comments:

1. The questions are not ethnic specific as I believe they are fine and will not incur bias.
4. & 5. See changes made to the demographics questionnaires.

An excellent instrument for your research.

APPENDIX G. RECRUITMENT LETTER AND FLYER

APPROVED
7404
George Mason University

Date

Dear [Mr. /Ms. LAST Name]:

I am a nursing doctoral student working on my doctoral dissertation at George Mason University in Fairfax, Virginia.

I am conducting a research study to explore the quality of life of partners of African American women with breast cancer.

I obtained your name and address from (source). You may be eligible to participate in this study if you are eighteen years or older, are an African American woman who has been at present or in the past diagnosed with breast cancer and have or had a husband or partner residing with you at the time of your diagnosis.

To participate in the study you and your partner are asked to sign the enclosed consent forms and return to me in the enclosed self-addressed, stamped envelope. Once this has been done then you, the African American woman will complete the questionnaire marked C and the African American male husband or partner will complete questionnaires marked D and E. Completion of the questionnaires should take approximately 12 minutes for the husband/partner and less for the woman. Once the questionnaires have been completed please return them in the enclosed self-addressed, stamped envelope marked questionnaires. If you have computer access and would prefer to complete the survey questionnaires on line please go to the secure site, Survey Monkey <http://netmail.verizon.com/netmail/driver?nimlet=showcanvas#>.

You and your partner/husband each will receive a \$20.00 Visa gift card once you have completed and returned the survey. In the packet is a smaller stamped envelope. Please write your address on it and return in the larger envelope. Gift cards will be mailed to you. If you elect to complete the survey on line, a number will be provided to you at the end of the survey. Please call me or write me at the address below. Provide the survey number given to you and your address. Your gift cards will be mailed to you.

The results of this research study may be published, but the questionnaires are anonymous and your name will not be known.

Your participation in the study is voluntary. You may choose to withdraw from the study at any time. You will not receive any personal health benefits as a result of your participation in this research study. However, it is hoped that the results will help gain a better understanding of African American couples who go through the breast cancer experience.

If you have questions regarding this study please call me at (540) 848-0091.

Sincerely,

Patricia C. Smith
George Mason University Nursing Doctoral Student
Post Office Box 7582
Fredericksburg, Virginia 22401

This research study has been approved by the George Mason University Human Subjects Review Board

APPROVED
7404
George Mason University

WANTED!

**African American women
who have or have had breast cancer
and your PARTNERS**



**to participate in an
important research study
answer a questionnaire
A \$40.00 Visa gift card will be given to couples
completing the survey**

**PLEASE contact
Patricia C. Smith, MSN, RN-C, FNP-BC
Certified Family Nurse Practitioner
(540) 848-0091**

OR

go on line to

**[https://www.surveymonkey.com/s/Demographics and Caregiver Quality of Life](https://www.surveymonkey.com/s/Demographics%20and%20Caregiver%20Quality%20of%20Life)
Survey**

APPENDIX H. INFORMED CONSENT FORMS

QUALITY OF LIFE OF THE PARTNERS OF AFRICAN AMERICAN WOMEN WITH BREAST CANCER

INFORMED CONSENT FORM FOR PARTNERS OF AFRICAN AMERICAN WOMEN WITH BREAST CANCER

RESEARCH PROCEDURES

This research is being conducted to examine the level of self-reported quality of life of husbands/partners of African American women with breast cancer. The study will explore the impact of African American women's breast cancer experience on African American male husbands'/partners' quality of life utilizing burden, disruptiveness, positive adaptation and financial burden from the questions in the surveys. If you agree to participate in this study, you will be asked to complete two surveys. It will take approximately thirteen minutes to answer the questions in the surveys.

RISKS

There are no foreseeable risks for participating in this research.

BENEFITS

There are no benefits to you as a survey participant other than to further research in assessing the quality of life of partners of African American women with breast cancer.

CONFIDENTIALITY

The data in this study will be confidential. An informed consent will be completed by you and returned to the researcher prior to your completing the survey. Names and other identifiers will not be placed on surveys or other research data.

PARTICIPATION

Your participation is voluntary and you may withdraw from the study at any time and for any reason. If you decide not to participate or if you withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled. A \$40.00 Visa gift card will be given to couples who complete and return the surveys.

CONTACT

This research is being conducted by Patricia Smith, nursing doctoral student at George Mason University. Ms. Smith may be contacted at (540) 847-7909 or psmithr@gmu.edu should you have questions or to report a research-related problem. You may contact George Mason University Office of Research Subject Protections at (703) 993-4121 if you have questions or comments regarding your rights as a survey participant.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

CONSENT

I have read this form and agree to participate in this study.

Name of Participant

Signature of Participant

Date of Signature

APPROVED
7404
George Mason University

**QUALITY OF LIFE OF THE PARTNERS OF
AFRICAN AMERICAN WOMEN WITH BREAST CANCER**

**INFORMED CONSENT FORM FOR
AFRICAN AMERICAN WOMEN WITH BREAST CANCER**

RESEARCH PROCEDURES

This research is being conducted to examine the level of self-reported quality of life of husbands/partners of African American women with breast cancer. The study will explore the impact of African American women's breast cancer experience on African American male husbands'/partners' quality of life utilizing burden, disruptiveness, positive adaptation and financial burden from the questions in the surveys. If you agree to participate in this study, you will be asked to complete a survey. The questions in the survey you are to complete will take approximately three minutes to answer. The questionnaires provided to your partner/ husband contain questions that pertain to you and his perceptions of your breast cancer experience.

RISKS

There are no foreseeable risks for participating in this research.

BENEFITS

There are no benefits to you as a survey participant other than to further research in assessing the quality of life of husbands/partners of African American women with breast cancer.

CONFIDENTIALITY

The data in this study will be confidential. An informed consent will be completed by you and returned to the researcher prior to your completing the survey. Names and other identifiers will not be placed on surveys or other research data.

PARTICIPATION

Your participation is voluntary and you may withdraw from the study at any time and for any reason. If you decide not to participate or if you withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled. A \$40.00 Visa gift card will be given to couples who complete and return the surveys.

CONTACT

This research is being conducted by Patricia Smith, nursing doctoral student at George Mason University. Ms. Smith may be contacted at (540) 847-7909 or psmithr@gmu.edu should you have questions or to report a research-related problem. You may contact George Mason University Office of Research Subject Protections at (703) 993-4121 if you have questions or comments regarding your rights as a survey participant.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

CONSENT

I have read this form and agree to participate in this study.

Name of Participant

Signature of Participant

Date of Signature

APPROVED
7404
George Mason University


APPENDIX I. HUMAN SUBJECTS REVIEW BOARD PERMISSION



Office of Research Subject Protections

Research Hall
4400 University Drive, MS 6D5, Fairfax, Virginia 22030
Phone: 703-993-4121; Fax: 703-993-9590

TO: Ann Maradiegue, College of Health and Human Services

FROM: Keith R. Bushey 
Chief of Staff, Office of Research

PROTOCOL: 7404 Research Category: Class Project (G)

PROPOSAL NO.: N/A

TITLE: Quality of Life of the Partners of African American Women with Breast Cancer

DATE: February 27, 2012

Cc: Patricia Smith

Thank you for submitting the documents necessary for continuing review of the above-cited protocol.

Upon re-review, this project was determined to be exempt by the Office of Research Subject Protections since it falls under DHHS Exempt Category 2, research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior.

Please note that all modifications to your research must be submitted to the Office of Research Subject Protections for review and approval prior to implementation. Any adverse events or unanticipated problems involving risks to subjects including problems involving confidentiality of the data identifying the participants must be reported to me in the GMU Office of Research Subject Protections and reviewed by the GMU Human Subjects Review Board.

GMU is bound by the ethical principles and guidelines for the protection of human subjects in research contained in The Belmont Report. Even though your data collection procedures are exempt from review by the GMU HSRB, GMU expects you to conduct your research according to the professional standards in your discipline and the ethical guidelines mandated by federal regulations.

If you have any questions, please do not hesitate to contact me at 703/993-3088.

APPENDIX J. SURVEY MONKEY DEMOGRAPHICS QUESTIONNAIRE FOR WOMEN AND MEN/CAREGIVER QUALITY OF LIFE

Demographics Questionnaire Women and Men / Caregiver Quality of Life
Woman's Consent Form
<p>QUALITY OF LIFE OF THE PARTNERS OF AFRICAN AMERICAN WOMEN WITH BREAST CANCER</p> <p>INFORMED CONSENT FORM FOR AFRICAN AMERICAN WOMEN WITH BREAST CANCER</p> <p>RESEARCH PROCEDURES This research is being conducted to examine the level of self-reported quality of life of husbands/partners of African American women with breast cancer. The study will explore the impact of African American women's breast cancer experience on African American male husbands/partners' quality of life utilizing burden, disruptiveness, positive adaptation and financial burden from the questions in the surveys. If you agree to participate in this study, you will be asked to complete a survey. The questions in the survey you are to complete will take approximately three minutes to answer. The questionnaires provided to your partner/ husband contain questions that pertain to you and his perceptions of your breast cancer experience.</p> <p>RISKS There are no foreseeable risks for participating in this research.</p> <p>BENEFITS There are no benefits to you as a survey participant other than to further research in assessing the quality of life of husbands/partners of African American women with breast cancer.</p> <p>CONFIDENTIALITY The data in this study will be confidential. An informed consent will be completed by you and returned to the researcher prior to your completing the survey. Names and other identifiers will not be placed on surveys or other research data.</p> <p>PARTICIPATION Your participation is voluntary and you may withdraw from the study at any time and for any reason. If you decide not to participate or if you withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled. There are no costs to you or any other party.</p> <p>CONTACT This research is being conducted by Patricia Smith, nursing doctoral student at George Mason University. Ms. Smith may be contacted at (540) 848-0091 or psmithr@gmu.edu should you have questions or to report a research-related problem. You may contact George Mason University Office of Research Subject Protections at (703) 993-4121 if you have questions or comments regarding your rights as a survey participant.</p> <p>This research has been reviewed according to George Mason University procedures governing your participation in this research.</p> <p>1. CONSENT</p> <p><input type="radio"/> I have read this form and agree to participate in this study.</p>
Woman's Questionnaire
<p>2. What is your age?</p> <div></div>
<p>3. What is your race?</p> <div></div>

Demographics Questionnaire Women and Men / Caregiver Quality of Life

4. Are you currently?

- ☐ employed for wages
- ☐ self-employed
- ☐ unemployed
- ☐ unable to work
- ☐ retired

5. Has there been a change in your employment since your breast cancer illness?

- ☐ Yes
- ☐ No

Woman's Questionnaire Continued

6. Are you currently?

- ☐ married
- ☐ never been married
- ☐ living with a partner

7. Were you previously divorced, separated or living apart from your partner prior to your breast cancer illness?

- ☐ Yes
- ☐ No

8. How long have you been with your wife/partner? Please answer with Months ___ and Years ___

Woman's Questionnaire Continued

9. What is the highest number of years of school you completed?

If did not attend school type '0'

Number of years

Demographics Questionnaire Women and Men / Caregiver Quality of Life

10. Do you have health insurance?

- ☐ Yes, Private Insurance
- ☐ Yes, Medicare
- ☐ Yes, Medicaid
- ☐ No

Woman's Questionnaire Continued

11. What is your faith/religion if any?

12. Has your faith or religion assisted you in coping with your breast cancer experience?

- ☐ Yes, a great deal
- ☐ Yes, some help
- ☐ Yes, not much help
- ☐ Not applicable
- ☐ No

Woman's Questionnaire Continued

13. When were you diagnosed with breast cancer?

14. Please check the cancer stage at diagnosis.

- ☐ Stage I
- ☐ Stage II
- ☐ Stage III
- ☐ Stage IV

15. Did you have chemotherapy?

- ☐ Yes
- ☐ No

16. If yes to question 15, how long ago? Please answer in Months ____ Years ____

Demographics Questionnaire Women and Men / Caregiver Quality of Life

17. Did you have radiation?

- ☐ Yes
☐ No

18. If yes to question 17, how long ago? Please answer in Months ____ Years ____

19. Did you have hormone therapy?

- ☐ Yes
☐ No

20. If yes to question 19, how long ago? Please answer in Months ____ Years ____

Woman's Questionnaire Continued

21. Did you have a?

- ☐ Mastectomy
☐ Lumpectomy
☐ Both
☐ No Surgery

22. Do/did you need help with your activities of daily living after surgery, during chemotherapy or radiation therapy?

- ☐ Yes
☐ No

23. If yes to question 22, how many Minutes ____ Hours ____ a day?

24. Including yourself, how many people live in your household?

25. If others live in the household, do they contribute to the household income?

- ☐ Yes
☐ No

Demographics Questionnaire Women and Men / Caregiver Quality of Life

26. Are there any children in your household under the age of 18?

☐ Yes

☐ No

27. If yes to question 26, what are their ages?

28. What is your {combined} annual household income?



End of Woman's Questionnaire



Man/Partner's Questionnaire

The following section is to be completed by
the Man/Partner.

Man/Partner's Consent Form

Demographics Questionnaire Women and Men / Caregiver Quality of Life

QUALITY OF LIFE OF THE PARTNERS OF
AFRICAN AMERICAN WOMEN WITH BREAST CANCER

INFORMED CONSENT FORM FOR
PARTNERS OF AFRICAN AMERICAN WOMEN WITH BREAST CANCER

RESEARCH PROCEDURES

This research is being conducted to examine the level of self-reported quality of life of husbands/partners of African American women with breast cancer. The study will explore the impact of African American women's breast cancer experience on African American male husbands/partners' quality of life utilizing burden, disruptiveness, positive adaptation and financial burden from the questions in the surveys. If you agree to participate in this study, you will be asked to complete two surveys. It will take approximately thirteen minutes to answer the questions in the surveys.

RISKS

There are no foreseeable risks for participating in this research.

BENEFITS

There are no benefits to you as a survey participant other than to further research in assessing the quality of life of partners of African American women with breast cancer.

CONFIDENTIALITY

The data in this study will be confidential. An informed consent will be completed by you and returned to the researcher prior to your completing the survey. Names and other identifiers will not be placed on surveys or other research data.

PARTICIPATION

Your participation is voluntary and you may withdraw from the study at any time and for any reason. If you decide not to participate or if you withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled. There are no costs to you or any other party.

CONTACT

This research is being conducted by Patricia Smith, nursing doctoral student at George Mason University. Ms. Smith may be contacted at (540) 848-0091 or psmithr@gmu.edu should you have questions or to report a research-related problem. You may contact George Mason University Office of Research Subject Protections at (703) 993-4121 if you have questions or comments regarding your rights as a survey participant.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

29. CONSENT

☐

I have read this form and agree to participate in this study.

Man/Partner's Questionnaire

30. What is your age?

31. What is your race?

Demographics Questionnaire Women and Men / Caregiver Quality of Life

32. Are you currently?

- ☐ employed for wages
☐ self-employed
☐ unemployed
☐ unable to work
☐ retired

33. Has there been a change in your employment since your partner's breast cancer illness?

- ☐ Yes
☐ No

Man/Partner's Questionnaire Continued

34. Are you currently?

- ☐ married
☐ never been married
☐ living with a partner

35. Were you previously divorced, separated or living apart from your partner prior to your breast cancer illness?

- ☐ Yes
☐ No

36. How long have you been with your wife/partner? Please answer with Months ____ and Years ____

Man/Partner's Questionnaire Continued

37. What is the highest number of years of school you completed?

If did not attend school type '0'

Number of years

Demographics Questionnaire Women and Men / Caregiver Quality of Life

38. Do you have health insurance?

- ☐ Yes, Private Insurance
- ☐ Yes, Medicare
- ☐ Yes, Medicaid
- ☐ No

Man/Partner's Questionnaire Continued

39. What is your faith/religion if any?

40. Has your faith or religion assisted you in coping with your wife's/partner's breast cancer experience?

- ☐ Yes, a great deal
- ☐ Yes, some help
- ☐ Yes, not much help
- ☐ Not applicable
- ☐ No

Man/Partner's Questionnaire Continued

41. Did/does your wife/partner need help with her activities of daily living after surgery, during chemo therapy or radiation therapy?

- ☐ Yes
- ☐ No

42. If yes to question 41, how many Minutes ___ Hours ___ a day?

43. Do you have any health problem that affect your ability to give health care?

- ☐ Yes
- ☐ No

44. If yes to question 43, please explain.

Caregiver Quality of Life

The following are statements that other people caring for loved ones with cancer have said are important.

Please indicate how true each statement was/has been for you.

45. It bothers/bothered me that my daily routine is/was altered.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

46. My sleep is/was less restful.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

47. My daily life is/was imposed upon.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

48. I am/was satisfied with my sex life.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

Demographics Questionnaire Women and Men / Caregiver Quality of Life

49. It is/was a challenge to maintain my outside interests.

- ☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

50. I am/was under a financial strain.

- ☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

51. I am/was concerned about our insurance coverage.

- ☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

52. My economic future is uncertain.

- ☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

53. I fear my loved one will die.

- ☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

54. I have more of a positive outlook on life since my loved one's illness.

- ☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

55. My level of stress and worries has increased.

- ☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

56. My sense of spirituality has increased.

- ☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

57. It bothers/bothered me, limiting my focus to day-to-day.

- ☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

58. I feel/felt sad.

- ☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

59. I feel/felt under increased mental strain.

- ☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

Demographics Questionnaire Women and Men / Caregiver Quality of Life

60. I get/received support from my friends and neighbors.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

61. I feel/felt guilty.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

62. I feel/felt frustrated.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

63. I feel/felt nervous.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

64. I worry about the impact my loved one's illness has had on my children or other family members.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

65. I have/had difficulty dealing with my loved one's changing eating habits.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

66. I have developed a closer relationship with my loved one.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

67. I feel/felt adequately informed about my loved one's illness.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

68. It bothers/bothered me that I need to be available to chauffeur my loved one to appointments.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

69. I fear/feared the adverse effects of treatment on my loved one.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

Demographics Questionnaire Women and Men / Caregiver Quality of Life

70. The responsibility I have/had for my loved one's care is/was overwhelming.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

71. I am glad that my focus is on getting my loved one well.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

72. Family communication has increased.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

73. It bothers/bothered me that my priorities have changed.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

74. The need to protect my loved one bothers/bothered me.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

75. It upsets/upset me to see my loved one deteriorate.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

76. The need to manage my loved one's pain is/was overwhelming.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

77. I am/was discouraged about the future.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

78. I am satisfied with the support I get from my family.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

79. It bothers/bothered me that other family members have not shown/did not show interest in taking care of my loved one.

☐ Not at all ☐ Somewhat ☐ A little bit ☐ Quite a bit ☐ Very Much

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