Social Support and Intimate Partnerships in African American Women with Breast Cancer

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Social Support and Intimate Partnerships in African American Women with Breast Cancer
by
Tess Thompson

A dissertation presented to the
Graduate School of Arts & Sciences
of Washington University in
partial fulfillment of the
requirements for the degree
of Doctor of Philosophy

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ABSTRACT OF THE DISSERTATION

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by

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Professor Melissa Jonson-Reid, Chair

This mixed methods study investigated social support in African American breast cancer patients in one Midwestern metropolitan area. The study includes a quantitative analysis of social support in 227 African American breast cancer patients participating in a quality of life study, as well as a qualitative component involving a subsample of 15 married participants. In the larger sample, growth curve models were used to assess factors contributing to initial levels of perceived social support and change in social support over time. Interviews with women in the qualitative study allowed an in-depth exploration of how breast cancer affected women’s relationships with their partners. Results from both parts of the study show that there is variability in women’s and couples’ adaptation to breast cancer. Clinicians should consider breast cancer patients’ psychosocial context and provide interventions for women with low levels of social support or women who experience declines in support.
Chapter 1: Statement of the Problem, Background, and Specific Aims

Breast cancer is the most commonly diagnosed cancer among White and African American women (Siegel, Ma, Zou, & Jemal, 2014; American Cancer Society, 2013). More than 200,000 women are diagnosed with breast cancer every year, and over 3 million breast cancer survivors are currently living in the United States (DeSantis et al., 2014). Although African American women are diagnosed with breast cancer at similar rates compared to White women, African American women are 42% more likely to die of the disease (DeSantis et al., 2016). African American women are also less likely than White women to adhere to follow-up care recommendations, including clinic visits and surveillance mammography (Advani et al., 2014). Only 78% of African American women diagnosed with breast cancer survive five years, compared to 92% of White women (Office of Minority Health, 2013). This disparity in outcomes has been attributed to a variety of factors, including stage at diagnosis, type of tumor, access to care, and socioeconomic status, but much of the difference remains unexplained (American Cancer Society, 2013).

One approach to explaining health disparities in outcomes between African Americans and Whites diagnosed with breast cancer is to investigate social determinants of health (Hudson & Gehlert, 2015). Social support and intimate partnerships are key social determinants of health in the general population (Umberson & Montez, 2010), but little is known about how these social determinants affect health over time in African American women with breast cancer. Filling this gap in knowledge can help inform interventions to support African American breast cancer
survivors and their partners. This study analyzes change in relationships and social support over time in African American women with breast cancer; investigates how those changes affect outcomes including perceived health, depressive symptoms, and use of surveillance mammography; and explores how a subsample of married women perceive breast cancer to have affected both their relationships and their partners’ health and well-being.

1.1 Background

One of four overarching goals of Healthy People 2020 is to “[c]reate social and physical environments that promote good health for all” (U.S. Department of Health and Human Services, 2014). Healthy People 2020 states that individual health is determined in part by “the resources and supports available in our homes, neighborhoods, and communities” (U.S. Department of Health and Human Services, 2014). A growing body of work has analyzed the effects of contextual factors on health (e.g., Krieger, 2011; Holmes et al., 2008), including in the context of specific diseases such as cancer (e.g., Hudson & Gehlert, 2015; Gehlert, 2014). Intimate partnerships and social support are important contextual factors that can affect health both in the general population and in cancer patients.

1.2 Psychosocial Context of Cancer Survivorship

Over the past century, the biomedical and social context of cancer has shifted; whereas most cancer patients previously had a poor prognosis, many will now live for years following diagnosis, and the majority of people diagnosed with cancer now survive for at least five years (Centers for Disease Control and Prevention, 2014; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). These changes have led to an increasing number of long-term cancer survivors. At the beginning of 2014, there were nearly 14.5 million cancer survivors in the United States, a
number that is estimated to grow to almost 19 million people in the next decade (DeSantis et al., 2014). Given this overall increase in cancer survivorship, attention has turned to the importance of improving quality of life—including physical and emotional health—among cancer survivors (Hagedoorn et al., 2008). A 2006 report from the Institute of Medicine, for example, encourages the use of survivorship care plans that take into account survivors’ psychosocial needs (IOM, 2006).

Survivorship research has shown that, although many patients adjust well after cancer diagnosis and treatment, some remain troubled by psychosocial and physical problems for years. For instance, in a study of 752 cancer survivors approximately one year after diagnosis, the majority reported fears about the future or concerns about physical symptoms such as fatigue (Baker, Denniston, Smith, & West, 2005). In a systematic review of symptoms in survivors of breast, prostate, gynecologic, and colorectal cancer, Harrington and colleagues found that symptom burden was comparable across those types of cancer, and that pain, fatigue, and depressive symptoms could persist for longer than 10 years post-treatment (Harrington, Hansen, Moxkowitz, Todd, & Feurstein, 2010). One study found that a diagnosis of cancer was associated with an increase in depressive symptoms that could persist for years, although survivors did tend to adapt over time, and there was considerable variability between people in the course of depressive symptoms after cancer (Infurna, Gerstorf, & Ram, 2013). Researchers have shown that many breast cancer patients experience good quality of life, although they may remain troubled by specific cancer-related symptoms, even years after diagnosis (Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2005). In short, although many long-term cancer survivors adapt well to the disease, some face prolonged physical and psychosocial problems.
An increasing research focus on survivorship has brought attention to ways in which personal relationships such as intimate partnerships affect psychosocial and physical health in the context of cancer. Earlier research has indicated that, compared to unmarried people, married people with cancer were diagnosed at earlier stages, were more likely to receive treatment, and had higher rates of survival (Goodwin, Hunt, Key, & Samet, 1987). A more recent study replicated these results: Using data from over 700,000 cancer patients in the Surveillance, Epidemiology and End Results (SEER) database, researchers found that married people were less likely than unmarried people to have metastatic cancer, more likely to receive recommended treatment, and less likely to die from cancer (Aizer et al., 2013). For several cancers, including breast cancer, the authors reported that effect size of the survival benefit being married was greater than effect sizes for survival seen in previous research for chemotherapy. Effects of being married on diagnosis, treatment, and survival were stronger for men than for women and held even after adjustments for demographic characteristics, including income. The results suggest that social support from marriage is one of the main factors influencing the “survival gap” between married and unmarried people with cancer, especially for men (Aizer et al., 2013).

1.3 Intimate Partnerships and Social Support in the United States

Intimate partnerships—including marriage, cohabiting, and dating relationships—play a key role in the lives of many American adults. In the past half-century, family patterns in the U.S. have changed dramatically, and patterns of intimate partnerships are more varied than ever before (Cherlin, 2009). It remains the case, however, that the vast majority of American adults are in intimate partnerships at some point in their lives (Cherlin, 2009). Recent analysis of the National Survey of Family Growth, for example, found that the majority of men and women ages
25-44 are in a married or cohabiting relationship with an opposite-sex partner (Goodwin, Mosher, & Chandra, 2010), and most American adults will marry at some point (Cherlin, 2009). There are, however, differences in family formation patterns by socioeconomic status and race. People of higher educational status are more likely to marry and less likely to divorce compared to people with lower educational status; the differences in marriage are especially stark between people who have at least a bachelor’s degree and those who do not (Pew Research Center, 2010; McLanahan, 2004). Marriage patterns also differ by race (Kreider & Ellis, 2011; Goodwin et al., 2010), with African Americans marrying at lower rates and divorcing at higher rates than Whites (Banks & Gatlin, 2005).

In the general population, researchers have consistently found that stable intimate partnerships—particularly marriage—are linked to better health (e.g., Rendall, Weden, Favreault, & Waldron, 2011; Holt-Lunstad, Birmingham, & Jones, 2008; Waite, 1995). Studies have found that married people generally fare better than unmarried people in terms of both physical health (Umberson & Montez, 2010; Robles & Kiecolt-Glaser, 2003), mental health (Uecker, 2012; Holt-Lunstad et al., 2008; Marcussen, 2005; Simon, 2002; Brown, 2000; Umberson & Williams, 1999), and overall mortality (Rendall, Weden, Favreault, & Waldron, 2011; Manzoli, Villari, Pirone, & Boccia, 2007; Johnson, Backlund, Sorlie, & Loveless, 2000; Umberson & Williams, 1999; Waite, 1995). In addition to the associations with relationship status, researchers have also found that the quality of intimate partnerships such as marriage has important effects on health, with higher quality relationships associated with better health (Robles, Slatcher, Trombello, & McGinn, 2014).

One of the main ways intimate partnerships are believed to affect health and wellbeing is through the role of social support (Thoits, 2011; Umberson & Montez, 2010; Robles & Kiecolt-
Glaser, 2003). Social support, a term generally used to encompass functions provided by others in order to assist someone, is itself associated with health and wellbeing in the general U.S. population (Galea et al., 2011; Umberson & Montez, 2010; Uchino, 2009). Social support can promote both mental and physical health through many channels, including promoting positive health behaviors, enhancing perceptions of personal control, and providing a sense of purpose and meaning (Umberson & Montez, 2010). Such support is often conceptualized as including specific support functions (e.g., emotional support, informational support, tangible/instrumental support); emotional support in particular has a strong link to health (Thoits, 2011; see Chapter Two for more information about these functions). The distinction between perceived support (the belief that support is available if needed) and received support (reports specific instances of receipt of certain types of support) is an important one in health research, with perceived support often being more strongly linked with health compared to received support (Uchino, 2009).

Findings from numerous studies suggests that these positive associations between intimate partnerships, social support and health also hold among African Americans. Researchers have found African Americans see a survival benefit from marriage (Su, Stimpson, & Wilson, 2015; Johnson et al., 2000). Taylor, Chae, Chatters, Lincoln, and Brown (2012) found in their analysis of National Survey of American Life data that African Americans who were married/partnered had lower odds of major depressive disorder that those who were previously married or those who were not currently in a relationship. Kiecolt, Hughes, and Keith (2008) analyzed National Comorbidity Study data and concluded that the overall effects of intimate partnerships on mental health were largely similar for Whites and African Americans, although in some cases they found the positive aspects of relationships had stronger effects for African Americans. Whereas African Americans had a lower rate of marriage than Whites, the
effects of marriage were more beneficial for the mental health of African Americans than for Whites (Kiecolt et al., 2008). Findings from some studies indicate that African Americans report lower relationship quality than Whites (Bulanda & Brown, 2007). One study suggested that negative partner behaviors such as infidelity, physical violence, or not showing affection may explain these racial differences (Broman, 2005). Umberson, Williams, Thomas, Liu, and Thomeer (2014) found that African American men were particularly susceptible to experiencing “chains of adversity” whereby childhood adversity led to increased relationship strain in adulthood, which adversely affected their health. These results suggest both that stable intimate partnerships among African Americans are associated with better health and wellbeing, and also that these relationships may face additional challenges compared to similar partnerships among Whites.

1.4 Intimate Partnerships and Social Support Among Cancer Survivors

Both social support and relationships are associated with health and wellbeing in the context of cancer. Results from ten studies included in a systematic review of long-term (>5 years) survivors of breast cancer (inclusion criteria: peer-reviewed studies published in English, German, or Dutch that included standardized quality of life measures) provided strong evidence of an association between higher social support and higher quality of life, although evidence for the effects of marital status was inconclusive (Mols et al., 2005).

The coping styles used within a partnership may also affect quality of life. In a descriptive longitudinal study of 26 primarily Caucasian women with various types of cancer, researchers found that mutually supportive relationships demonstrating relationship-focused coping were linked to psychosocial adjustment in patients a year and a half after a cancer
diagnosis (Kayser & Sormanti, 2002). The presence of cancer may also be associated with relationship-related problems: One study found that a year after diagnosis, substantial numbers of cancer survivors reported concerns about sexuality (41%), concerns about providing financially for one’s family (26%), problems communicating with a partner (20%), and problems with family/children in general (14%) (Baker et al., 2005). Female survivors were approximately twice as likely as men to report problems with family/children, and younger survivors (under 55) were more likely than older survivors to report family-related problems (Baker et al., 2005).

1.5 Dyadic Cancer Research

In addition to examining the role of relationships in psychosocial sequelae of cancer for individuals, researchers have recently investigated the effects of cancer on both members of an intimate partnership. This dyadic research, which takes the couple as one level of analyses, can be used to examine crossover effects between partners’ physical and mental health in the context of a cancer diagnosis. This type of research, which uses innovative statistical techniques such as the Actor-Partner Interdependence Model (APIM; Kenny, Kashy, & Cook, 2006; see Chapter Two), multilevel modeling, and/or structural equation modeling, has spanned a variety of cancer sites but has focused predominantly on White patients and partners.

Findings from dyadic research suggest that cancer has effects not only on a patient’s health and wellbeing, but also on the health and wellbeing of a patient’s partner. A longitudinal analysis of over 7,000 participants in the Health and Retirement Study (84% White, 9% African American, 7% Hispanic, and 1% other race/ethnicity) found that a spouse’s development of a serious chronic health condition (including cancer) was associated with female partners’ reporting lower mental health and male partners’ reporting lower overall health (Valle et al.,
A longitudinal study of husband-wife dyads in the Medical Expenditures Panel Survey found that couples in which one partner had cancer demonstrated small but significant mental and physical health crossover effects between both patients and partners, effects not seen in couples without cancer (Litzelman, Green, & Yabroff, 2016). The authors found that, over a period of approximately one year, dyads affected by cancer showed greater crossover of elevated depressed mood from partner to patient than vice versa (Litzelman et al., 2016). In one cross-sectional study of 85 dyads composed of breast cancer patients (85% White, 14% Hispanic, and 1% other race/ethnicity) and their partners (predominantly spouses or “significant others”), researchers found that when patients reported high levels of stress and depressive symptoms, their partners experienced worse physical health (Dorros, Card, Segrin, & Badger, 2010). In a multilevel longitudinal analysis of couples facing lung cancer (N = 77 dyads, with patients 94% White), declines in physical functioning of patients over a 12-month period were associated with higher levels of depressive symptoms in spouses (Lyons et al., 2014). Using cross-sectional data from married breast and prostate cancer dyads (N = 168 dyads, over 90% White, and an average of about 2 years post-cancer-diagnosis), Kim et al. (2008) found that, regardless of whether women were patients or partners, their higher psychological distress was associated with husbands’ decreased physical health; dissimilarity of distress among both members of a couple was associated with poorer mental health among female partners of prostate cancer patients, whereas for husbands, regardless of role, dissimilarity in distress was associated with better physical health. In analyses of lung and colorectal cancer patients (N = 398 dyads, with patients who were 79% White, 15% African American, 3% Hispanic, and 3% other race/ethnicity), Kim et al. (2015) found crossover effects between mental and physical health that differed for men and women. When female patients had higher levels of depressive symptoms, caregivers (who
were predominantly spouses) had poorer physical health and better mental health, whereas when male patients had higher levels of depressive symptoms, caregivers experienced only poorer mental health.

Taken together, these findings suggest that couples’ mental and physical health are often interdependent, but the types of influence may vary by gender, role (patient versus caregiver), and type of cancer. One weakness of many dyadic cancer studies is the use of samples that are predominantly White, highly educated, and affluent. It should also be noted that some of the studies (e.g., Kim et al., 2008; Dorros et al., 2010) rely on cross-sectional data; although these studies can suggest important associations, the lack of temporal information makes determining causal relationships impossible. Some of the studies (e.g., Kim et al., 2008; Dorros et al., 2010; Valle et al., 2013) also combine different types of cancer, which can be problematic given the different trajectories of various cancer types and may mask significant findings, especially when gender-specific cancers are combined within a sample (Hagedoorn et al., 2008). Still, this is a promising line of research that will benefit in the future from longitudinal work using more diverse samples in order to determine whether the results generalize to different populations.

1.6 Social Support, Intimate Partnerships, and Breast Cancer Survivorship

The current study focuses on social support and relationships in the particular context of breast cancer. Prior research has found that social support plays an important role in quality of life and health outcomes after breast cancer diagnosis and treatment (Høyer et al., 2011; Epplein et al., 2011; Courten et al., 1996). Lower levels of social support during the time of diagnosis and treatment have been associated with poorer mental health outcomes such as development of depression and anxiety (Hill et al., 2011; Patten, Williams, Lavorato, & Bulloch, 2010;
Schroevers, Ranchor, & Sanderman, 2003). Greater social support has been associated with lower mortality (Kroenke et al., 2013; Pinquart & Duberstein, 2010; Chou, Steward, Wild, & Bloom, 2010), greater posttraumatic growth (Schroevers, Helgeson, Sanderman, & Ranchor, 2010), better role functioning (Bloom & Kessler, 1994), increased physical activity (Barber, 2012), better physical health (Ganz et al., 2003), and lower levels of distress (Andreu et al., 2012).

Levels of social support in breast cancer patients may change over time. Prior work has suggested that many women report having increased support around the time of cancer diagnosis but that this support often decreases over time (Den Oudsten, Van Heck, Van der Steeg, Roukema, & De Vries, 2010; Courtens et al., 1996; Bloom & Kessler, 1994; Levy et al., 1992), a decrease that may be associated with negative psychosocial outcomes (Thompson et al., 2013). Not all studies have found a decline in social support, however. Leung, Pachana, and McLaughlin (2014) found that scores on the Medical Outcomes Study Social Support questionnaire (MOS-SS) were stable among Australian breast cancer patients when compared from time of diagnosis to three years later. Likewise, Ganz et al. (2002) surveyed long-term breast cancer survivors and found no change in MOS-SS scores from baseline (mean 3.4 years after diagnosis) to follow-up (mean 6.1 years after diagnosis). These mixed findings suggest that declines in social support may not continue indefinitely after diagnosis, and that it is important to consider the time intervals when social support is measured. In particular, these findings suggest that it may be particularly important to monitor social support in the first few years following a breast cancer diagnosis.

Partners are important sources of support for many women with breast cancer, and this support is often mutual (Kayser & Scott, 2008). Similar to findings from studies that include a
variety of cancer sites (Aizer et al, 2103; Goodwin, Hunt, Key, & Samet, 1987), one study using national data from over 32,000 women with breast cancer found that patients who were married were diagnosed at earlier stages, more likely to have definitive therapy, and less likely to die of breast cancer, results that the researchers attributed to social support and social networks (Osborne, Ostir, Du, Peek, & Goodwin, 2005).

1.7 Breast Cancer Survivorship Among African Americans

A much smaller body of research has investigated relationships and social support in African American women with breast cancer. Hudson and Gehlert (2015) contend, “Social factors play an important yet underestimated role in the development of breast cancer and increased likelihood of mortality among Black women” (p. 241). A full understanding of the nature of this relationship remains unclear. Most of the research into relationships and social support among African American breast cancer survivors has suggested that both are important, although some findings about levels of social support have been mixed. One study found that higher perceived emotional social support was associated with a moderate decrease in all-cause mortality among African American women with breast cancer (Soler-Vila et al., 2003). In another sample of breast cancer patients from multiple racial/ethnic groups, the authors found that perceived social support scores on the Medical Outcomes Study Social Support questionnaire (MOS-SS) were higher for African Americans than for women in other racial/ethnic groups (Giedzinska, Meyerowitz, Ganz, & Rowland, 2004); scores on the Dyadic Adjustment Scale (DAS), which measures relationship quality, did not differ by race/ethnicity. In contrast, a cross-sectional study of patients with various types of cancer found that African Americans reported lower perceived social support than Whites, and higher levels of social support were associated with higher mental health quality of life in African Americans but not in
Whites (Matthews, Tejeda, Johnson, Berbaum, & Manfredi, 2012). Another cross-sectional study found that, although the majority of African American breast cancer survivors (79%) were not in long-term relationships, those who were in such relationships reported significantly more social support from their partners compared to control African American women without cancer (after adjusting for income and education) (Von Ah, et al., 2012). This suggests that, in some contexts, a diagnosis of cancer may prompt partners to provide more support than they otherwise would.

There is also some indication from qualitative research with African American patients suggesting that breast cancer may strain intimate partnerships. One qualitative study of breast cancer patients of a variety of races/ethnicities found that many African American women reported decreased sexual desire and negative body image after cancer treatment that could affect relationships (Ashing-Giwa et al., 2004). Another qualitative study found that although most African American women who had partners reported receiving sufficient support from them, a minority reported their relationships had been seriously strained (Ashing-Giwa & Ganz, 1997). A more recent qualitative study of 33 African American breast cancer survivors ages 45 and younger (age range 25-45) found a strong impact of cancer on relationships (Lewis, Sheng, Rhodes, Jackson, & Schover, 2012). Most women in relationships reported that cancer interfered with their relationship somewhat or a great deal, and some women also reported that cancer had a strong negative emotional impact on their partners (Lewis et al., 2012). The authors point out that these high levels of relationship distress differ from findings in predominantly White samples, and they suggest that further research is needed to investigate how breast cancer affects relationships among African Americans (Lewis et al., 2012).

Longitudinal quantitative work may also be important in analyzing how the cross-sectional associations described above play out over time (Uchino et al., 2012). Prior growth
curve analyses in early-stage breast cancer patients (Thompson et al., 2013) found that in the two years following diagnosis, being African American was associated both with higher initial levels of perceived social support in patients and a steeper decline in social support over time. In multivariate analyses, partnered women demonstrated higher social support. Although African Americans were more likely to report higher levels of social support when partnership status was held constant, in that sample African American women were only half as likely to report being partnered compared to White women (Thompson et al., 2013).

1.8 Gaps in the Literature

Although research on general health in the context of breast cancer has demonstrated the importance of intimate partnerships and social support to mental and physical health, significant gaps in the literature remain. In order to reduce health disparities and inform culturally appropriate interventions for African American women with breast cancer, we need to understand more about how social support and intimate partnerships function in this population over time. It is important to move beyond the largely cross-sectional descriptive quality of life research and analyze dynamic patterns of the effects of relationships and social support on well-being of breast cancer survivors in this population. Knowledge about the predictors and the effects of changes in relationships and social support may hold promise for informing psychosocial interventions for breast cancer patients and their partners. The current study adds to the literature by using longitudinal analyses of a relatively large sample of African American breast cancer survivors to examine how social support and relationships may change over time following a cancer diagnosis.

In addition, we need to know more about how cancer affects both members of a partnership. To date, dyadic research involving cancer patients and partners has been almost
completely limited to samples that are predominantly White and higher income. This is, in part, because large datasets that contain psychosocial and physical health data collected from both members of a partnership are rare, leading most researchers to rely on convenience samples from only one medical center. These samples have often been relatively homogenous in terms of race, socioeconomic status, and/or sexual orientation, and article after article notes this lack of diversity in its limitations section (e.g., Lyons, et al., 2014; Regan et al., 2012; Badr & Carmack Taylor, 2008; Segrin, Badger, Dorros, Meek, & Lopez, 2007). Although the initial results of dyadic data analyses have provided important information about how couples cope with cancer together, as the field advances it is crucial to recruit samples that are diverse along a variety of dimensions. The current study helps to fill this gap by collecting preliminary information about how African American couples face cancer together in order to inform future quantitative work and suggest directions for dyadic intervention.

1.9 Specific Aims

This mixed methods study was made up of two parts: a quantitative component that examined social support over time in a sample of African American women using data drawn from a longitudinal quality of life study, and a qualitative component that used interviews to examine how married women perceived cancer to have affected their intimate partnerships and their partners’ health and wellbeing. It is hoped that findings from this study will help inform the future development of culturally appropriate interventions that incorporate key social determinants of health such as social support in order to reduce disparities in outcomes for breast cancer survivors.

This study addressed the following specific aims:
Aim 1: Examine perceived social support and relationship status over time in African American women newly diagnosed with breast cancer.

H1: Perceptions of social support will decline significantly over time.

H2: Individuals’ change in social support over time (slope) and stable levels of social support (intercept) will be predicted by demographic variables, psychosocial variables, health variables, and cancer-related variables.

H3: Greater decline in social support and lower social support intercept will be associated with lower general health, higher levels of depressive symptoms, and less likelihood of surveillance mammography at two-year follow-up (controlling for levels of health and depressive symptoms at baseline).

Aim 2: Use qualitative methods to explore the effects that African American married women perceive breast cancer to have had on their relationships and how they perceive breast cancer to have affected their partners’ health and well-being.
Chapter 2: Theories and Conceptual Frameworks

A range of theories and conceptual frameworks have been developed to explain the association between intimate partnerships, social support, and health, both in terms of general health and in the context of particular diseases. This chapter will discuss issues of selection and confounding (particularly how socioeconomic status may confound the association between relationship status and health), provide an overview of several models and theories, and present the conceptual models underlying the current study.

2.1 Selection, Protection, or Confounding?

Many theories and conceptual models about intimate partnerships and health are based on the assumption of a causal relationship (Ross & Mirowsky, 2013). Establishing causality in the association between intimate partnerships and health is not an easy task, however; for obvious reasons, people cannot be randomized to, for example, marry, cohabit, or become widowed. The first issue that must be addressed is whether the association between intimate partnerships and health is due solely to confounding due to some other variable (e.g., socioeconomic status). To that end, it is important to adjust analyses for other demographic variables, including race, education, age, and economic resources (Ross & Mirowsky, 2013). Adjusting for economic variables may depend on the conceptual model underlying the research; some have argued that “socioeconomic status differences are such a fundamental part of the cohabitation and marriage picture in the United States that statistical models that include them may be over-controlling: discarding variation that is a basic part of the phenomena under study” (Cherlin, 2013, p. 65).
Several longitudinal studies have controlled for sociodemographic variables using survival analysis and found an association between marital status and mortality. Rendall, Weden, Favreault, and Waldron (2011) analyzed longitudinal data from the Survey of Income and Program Participation using discrete time hazard models and found a significant survival advantage for married people, even after controlling for sociodemographic characteristics. Likewise, Johnson, Backlund, Sorlie, and Loveless (2000) used Cox proportional hazard models to analyze data from a cohort of 281,460 people from the National Longitudinal Mortality Study and found that, after adjusting for socioeconomic factors, unmarried people had a higher relative risk of death.

An alternate to the hypothesis that relationship status has a causal association with health is that the health effects of relationships are due to the selection of healthy people into intimate partnerships. In other words, the association between relationship status and health may be due solely to the fact that healthier people may be more likely to get married or enter into and subsequently stay in long-term relationships. Although the idea that healthy people are more likely to marry may be intuitively appealing, there has been little consistent evidence that the association between health and marriage is solely due to selection. Longitudinal research has provided evidence that selection does not explain all the variance in the physical and psychological health effects due to relationship status (Marcussen, 2005; Murray, 2000; Brown & McDaid, 2003). In fact, there may be both positive and adverse selection into marriage; Lillard and Panis (1996) found that divorced men in poor health were likely to remarry sooner than divorced men in good health.

Both the National Survey of Families and Households (NSFH) and the National Longitudinal Study of Adolescent Health (Add Health) have provided longitudinal information
that has been used to analyze protection versus selection hypotheses. Findings from these analyses have been mixed. In a longitudinal analysis of NSFH data for adults who were unmarried and not cohabiting at baseline, no difference was found in baseline depression scores between people who were married versus cohabiting at follow-up, but at follow-up cohabiting couples exhibited higher levels of depression; the author concluded there was no evidence of selection into marriage on the basis of mental health (Brown, 2000). Simon (2002) also used NSFH data and found no discernible pattern of selection into marriage on the basis of mental health, although there was evidence that mental health partially affected selection out of marriage because people with poor mental health were more likely to divorce. Uecker (2012) analyzed the first three waves of data from Add Health and concluded that although married people showed lower levels of depression, there was no evidence for selection into marriage based on mental health; in fact, participants in Add Health who were married were more likely to have been depressed before marriage. Horn, Xu, Beam, Turkheimer, and Emery (2013), on the other hand, used twin and relative genetic data from a subpopulation of Add Health participants and found that the effects of entry into marriage on self-reported physical health in this young adult population could be explained by nonrandom selection into marriage (that is, shared genes among relatives and/or environment affected both health and partnership status). They also found that there were differences between partnered and unpartnered young adults in depression and health behaviors such as alcohol use that may affect health outcomes over the life course. Taken together, findings from these studies do not demonstrate a consistent pattern of mental health selection into marriage (whereby mentally healthier people are more likely to marry and people who are less mentally healthy are less likely to do so).
In short, the issues of selection and protection are complex, and past findings have been mixed. Although selection into and out of intimate partnerships based on mental and physical health may be a factor in the observed health benefits of marriage and other relationships, there has not been consistent evidence that these effects are due solely to selection of healthy people into intimate partnerships, and it seems likely that these partnerships offer significant protective effects on health (e.g., Cherlin, 2013).

2.2 Economic Resources Model

Another model explaining the general health benefits of intimate partnerships holds that partnerships often provide access to economic resources that are themselves associated with health (Carr & Springer, 2010; Ross, Mirowsky, & Goldsteen, 1990). Due to the legal privileges traditionally provided by marriage in the United States, an economic resources model is often used to account for health differences between people who are married and people who are not. Being married is, for example, associated with increased access to private health insurance (Zuvekas & Taliaferro, 2003). In economist Gary Becker’s influential book *Treatise on the Family* (1981), he argued that married people benefit from economies of scale, specialization, and combining resources within marriage (although Becker believed this economic benefit was declining in the late twentieth century). Waite (1995) contended that married people are more likely to accumulate wealth over time due both to higher wages and to differences in saving behavior that may be encouraged by social norms. Lundberg and Pollak (2014) argued that although cohabitation may be capable of providing many of the benefits ascribed to marriage (including specialization, economies of scale, and the pooling of resources), the legal institution of marriage has higher exit costs than marriage and thus provides a strong “inter-temporal commitment” that encourages partners to invest in the family. From this perspective, committed,
legally recognized partnerships—particularly marriage—benefit people by providing them with economic resources and stability. It makes sense that economic resources are an important pathway through which such relationships benefit health but, as noted above, economic factors do not seem to explain all of the variance in health between people who are in stable relationships and those who are not.

2.3 Social Support Theories

Many theories about the health benefits of relationships involve social support, a general concept that has been defined and subdivided in various ways. In an overview of the social support literature, Thoits (2011) identified the most commonly mentioned types of social support, including emotional support (“demonstrations of love and caring,… encouragement, and sympathy”), informational support (“provision of facts or advice that may help a person solve problems,” a category that sometimes includes appraisal support, or “feedback about the person’s interpretation of a situation and guidance regarding possible courses of action,” and instrumental support (“offering or supplying behavioral or material assistance with practical tasks or problems”) (p. 146). Of these functions, emotional support seems particularly important in its relationship to health (Thoits, 2011). The distinction between perceived support (the belief that support is available if needed) and received support (reports specific instances of receipt of certain types of support) may also be particularly salient in health research. In the general population, research has found a stronger association between perceived support and health compared to received support (Uchino, 2009), and perceived support is the focus of the current study.

For many years, stress-buffering models dominated the social support literature (Uchino, Bowen, Carlisle, & Birmingham, 2012). Those models posit that social support’s relationship to
health is important because social support moderates the effects of stressful life events such as illness or job loss. After an acute stressor such as a diagnosis of cancer, for example, a person might receive support from members of his or her social network that assists with coping (Thoits, 2011). From this perspective, intimate partnerships and other close personal relationships are important because they help buffer the effects of outside stressors on an individual. There have been explorations of psychological mediators between social support and physical health (Uchino et al., 2012; Lakey & Orehek, 2011), with the hypothesis that mental health disorders such as anxiety and depression may link social support and physical health. Empirical support for stress-buffering models has been mixed, however. No consistent psychological mediators (e.g., anxiety or depression) have been found between social support and physical health outcomes (Lakey & Orehek, 2011; Uchino et al., 2012). Some researchers suggest that the processes by which social support affects health may be, at least in part, unconscious and automatic, or influenced by relational processes that can only be measured at the dyadic or family level (Feeney & Collins, 2014; Uchino et al., 2012). Hagedoorn et al. (2008) also point out that, although many cancer researchers have predicated their conceptual models on the assumption that a cancer diagnosis is a uniquely stressful experience, it may, in fact, be just one of many stressors faced by an individual or a couple. It is also important to acknowledge that intimate partnerships—especially poor quality relationships—may themselves be a source of stress (Umberson & Montez, 2010).

One conundrum found within the social support literature has been the weak connection between perceived social support (the belief that support is available if needed) and received social support (reports of specific supportive acts). Perceived support has been more strongly correlated with good health than has received support, but some studies have found either no
association or an inverse association with health (Uchino, 2009). Lakey and Orehek (2011) developed relational regulation theory (RRT) in part to help account for the discrepancy between perceived and received support, as well as the lack of association between received support and mental health outcomes. In contrast to theories that emphasize the effects of relationships in the presence of major stressors, RRT emphasizes the importance of “ordinary yet affectively consequential social interactions” in regulating emotion (p. 487). As Thoits (2011) explains, “An attentive review of ordinary days…would probably reveal that we routinely obtain demonstrations of love, caring, and understanding from intimates when we recount the day’s minor uplifts and hassles to one another” (p. 150). This concept of “everyday support” (Thoits, 2011; Lakey & Orehek, 2011) may help explain how social support functions in intimate partnerships and other close relationships. Thoits (2011) differentiates between supportive members of primary groups versus secondary groups. The primary group that provides social support in a person’s life tends to be smaller, informal, intimate, and lasting, while the secondary group of social support providers tends to be larger, more formal, less personal, and more easily joined and left (Thoits, 2011). This conception of support, in which perceived support is based largely on everyday interactions with one or more primary group members but occasionally on enacted support during times of stress (Feeney & Collins, 2014; Thoits, 2011), may help explain the health benefits of intimate partnerships and other close relationships. Uchino et al. (2012) hypothesize that support processes from people such as spouses may be primarily noncognitive and could be due, for example, to the simple recognition that a sympathetic person is nearby.

Social support may also have direct physiological effects on health. In a comprehensive review, Robles and Kiecolt-Glaser (2003) identify three primary direct physiological pathways by which intimate partnerships may affect health: cardiovascular function, immune function,
and neuroendocrine function. All three pathways are moderated by relationship quality, particularly the level of hostility or negativity in a relationship. In the realm of cardiovascular function, hostile interactions and relationship dissatisfaction have negative impacts on women’s blood pressure. In terms of endocrine function, hormones responsible for stress responses and metabolic regulation are affected by hostile or negative interactions. Immune function can also be dampened by hostile behavior. Robles and Kiecolt-Glaser conclude that “the key implication of this conceptualization is that physiological responses to stress have cumulative, long-term effects on health, including effects on tissue and organ systems, and progression and development of disease” (2003, p. 413). In other words, the short-term health effects of close relationships can lead to long-term effects. Lutgendorf and Sood (2011) provide an overview of ways that these effects may play out in the context of cancer. They summarize research showing that psychosocial factors such as stress, social support, and depression may affect factors such as gene expression and the tumor microenvironment, which can in turn enhance or inhibit the progression of cancer. In the future, such biologically informed work will be crucial for elucidating the mechanisms by which social factors affect biological processes.

2.4 Dyadic Theories and Frameworks

Researchers have developed a range of theories and frameworks to explain how processes of dyadic functioning affect health. Some of these theories address general processes that are posited to affect a variety of health outcomes, whereas others examine how couples face a health threat such as chronic illness. It is important to note that dyadic models focus only on the interaction between two people (often a couple in an intimate partnership) and do not account for the influence of other family members (e.g., children in the household). These theories and conceptual models include the Actor-Partner Interdependence Model (Kenny, Kashy, & Cook,
The Actor Partner Interdependence Model (APIM), a general model that can be used with many different kinds of dyads and outcomes, was developed by Kenny et al. (2006) to analyze the effects of partners on one another. The APIM (Figure 1) allows for analysis of both actor effects (that is, the effects of an individual’s characteristics) and partner effects (in this case, the effects of that individual’s intimate partner’s characteristics) on a particular outcome. The APIM has been increasingly used with dyads made up of cancer patients and intimate partners or other family members (e.g., Kim et al., 2015; Lyons et al., 2014; Dorros, Card, Segrin, & Badger, 2010). Although the APIM is primarily a statistical model, it is grounded in a conceptual model that emphasizes the interdependence of two people in a relationship. Kenny et al. argue that the dyad is “the fundamental unit of interpersonal interaction and interpersonal relations” (p. 1) and that “[b]efore we can have a genuinely interpersonal social science, our theories, research methods, and data analyses must take into account the truly interpersonal nature of the phenomena under study” (p. 3).
Figure 1 Basic Actor-Partner Interdependence model (APIM; Kenny, Kashy, & Cook, 2006).

The horizontal arrows show actor effects and the crossed arrows show partner effects. Not shown are the correlated errors for both members of the dyad.

Other models and theories relate more specifically to couples in intimate partnerships. Cutrona, Russell, and Gardner (2005) extend Bodenmann’s (2005) theory of dyadic coping to develop the Relationship Enhancement Model. This model is intended to build on direct effects models of perceived social support on relationships, but it includes relationship quality and stability as an important mediator of perceived social support’s effects on health. In this model, consistency of supportive responses affects attributions for partner behavior (i.e., whether behavior is seen as stemming from a fundamental attribute of a partner or from contextual factors). These attributions affect perceived partner support, which is also affected by a person’s attachment style and level of neuroticism. Perceived partner support affects trust (which also loops back and affects attachment style and attributions), which leads to relationship satisfaction and stability, which leads to health. This model is important because it includes relationship satisfaction and stability, which have well-established associations with health, and it suggests
factors that may be amenable to change (e.g., consistency of supportive responses or attributions for partner behavior). One drawback of the model, however, is that some of the more distal factors (e.g., neuroticism or attachment style) may be quite difficult to change. It should be noted that this model is not intended to explain couple functioning in the face of a specific illness or health threat, although it can be used to understand how relational processes might affect development of illness.

Berg and Upchurch (2007) propose a developmental-contextual model of couples coping with chronic illness across the adult life span. This model is distinctive in that it accounts for multiple effects of time; the authors state that the model “emphasizes that dyadic coping may be different across the life span, during specific historical times, and during different stages of dealing with the illness… as well as unfolding daily as spouses interact around chronic stressors” (p. 932). The model uses the dyad as the unit of analysis and portrays coping with, appraisal of, and adjustment to chronic illness as an inherently dyadic—and often reciprocal—process. These processes are affected by the sociocultural context, including factors such as culture and gender roles, as well as the proximal context, which includes factors such as marital quality and illness condition. The model extends to all kinds of chronic illnesses, which the authors distinguish from one another based on timeline (course of disease), consequences (symptoms or impairments), control (degree to which disease can be controlled), and identity (symptom labels). This model may be useful within the context of cancer research because it provides a framework for examining how different disease sites or cancer stages have wide variations in timeline, consequences, control, and identity (DeSantis et al., 2014).

Manne and Badr (2008) propose a cancer-specific model: the Relationship Intimacy Model of Couple Adaptation to Cancer, which offers “a couple-level perspective whereby the
cancer experience is viewed in relational terms” (p. 2542). In this model, couples engage in either relationship-enhancing behaviors, such as reciprocal self-disclosure, or relationship-compromising behaviors, such as avoidance and criticism. These processes have both a direct path to the outcome of couples’ relationship and psychological adaptation, as well as an indirect path through relationship intimacy. One innovation of their model for cancer research is that it emphasizes couples interacting as partners who both give and receive support, rather than focusing on one person as the “patient” and the other person as a “caregiver.”

These dyadic theories, which all have slightly different foci, are useful because they take the couple as the unit of analysis and conceptualize support and coping in relational terms. Strengths of the Relationship Enhancement Model (Cutrona, Russell, & Gardner, 2005) include a focus on relationship quality and relationship processes, which reflect empirical research (described in Chapter One). The Developmental-Contextual Model (Berg & Upchurch, 2007) is a broad model that can be applied to a range of chronic diseases or used to analyze varying trajectories for the same chronic disease; it is especially useful for longitudinal work and research that accounts for changes across the life course. The Relationship Intimacy Model of Couple Adaptation to Cancer (Manne & Badr, 2008) is innovative because it focuses on relational processes and the path to health through relationship intimacy in the context of cancer. One weakness of all of these models, however, is the lack of consideration of physical health outcomes for the partner without cancer. Given prior dyadic research that has shown crossover effects between physical and mental health of patients and partners, future models should include mental and physical health outcomes for both members of a dyad.
2.5 The Current Study

The current study was informed both by social support and dyadic models and theories. Aim 1 examined how social support changed in the two years following a diagnosis of breast cancer, as well as the consequences of those changes. Social support theories posit direct effects of social support on physical and mental health, and Aim 1 tested whether social support influenced levels of general health, levels of depressive symptoms, and one particular health behavior (receiving a surveillance mammogram). Researchers have begun to differentiate between social support in the context of a specific stressor (e.g., a breast cancer diagnosis) and more general support that is provided in everyday life. It is likely that, in the two years following a cancer diagnosis, both kinds of support are important. At the time of initial diagnosis and treatment, it is likely that social support is used to buffer immediate stressors, but over the course of the first two years of survivorship it is plausible that social support becomes more in line with the everyday support a woman perceived herself to have from a partner or other people prior to diagnosis (Kayser & Sormanti, 2002).

The qualitative study (Aim 2) was influenced by dyadic theories of crossover effects between partners’ health. Although the study was not dyadic (i.e., data were not collected from both partners), it examined how one partner believed her physical and mental health affected health outcomes in her partner. In reference to the APIM diagram in Figure 1, the study investigated participants’ perceptions of the diagonal arrow leading from Partner 1 to Partner 2. The findings from the qualitative study may be used to inform future dyadic research among African Americans with cancer.
Chapter 3: Methods

The current study had two parts: quantitative analyses examining social support and relationships in a sample of African American breast cancer survivors (Aim 1) and qualitative analyses of a subset of this sample exploring how a breast cancer diagnosis affected women’s intimate partnerships and their perceptions of effects on their partners’ health and well-being (Aim 2). This study included the following aims and hypotheses:

Aim 1: Examine perceived social support and relationship status over time in African American women newly diagnosed with breast cancer.

H1: Perceived social support will decline significantly over time.
H2: Individuals’ change in social support over time (slope) and stable levels of social support (intercept) will be predicted by demographic variables, psychosocial variables, health variables, and cancer-related variables.
H3: Greater decline in social support and lower social support intercept will be associated with lower general health, higher levels of depressive symptoms, and less likelihood of surveillance mammography at two-year follow-up (controlling for levels of health and depressive symptoms at baseline).

Aim 2: Use qualitative methods to explore the effects that African American married women perceive breast cancer to have had on their relationships and how they perceive breast cancer to have affected their partners’ health and well-being.

This chapter will cover the sources of the data, measurement of key constructs, the analysis plan, and protections for human subjects.
3.1 Sources of the Data
This study involved secondary data analysis of a longitudinal study of breast cancer patients, as well as analysis of new qualitative data collected from a subset of those participants.

3.1.1 Sample for Aim 1
Data for Aim 1 were drawn from the Survivor Stories Study, a longitudinal, randomized controlled trial of 227 African American women with breast cancer. Between 2009 and 2012, women treated for breast cancer at two St. Louis hospitals (Saint Louis University School of Medicine and Siteman Cancer Center at Washington University School of Medicine) were recruited by study staff, who sent letters approximately three days after patients’ surgical consultation for newly diagnosed breast cancer to invite them to participate in the study. Inclusion criteria included self-identifying as African American, being 30 years of age or older, and having a surgically confirmed first episode of ductal carcinoma in situ or invasive breast cancer (Stage I, II, or III). Exclusion criteria included having a previous diagnosis of breast cancer, having metastatic or stage IV breast cancer, having had a bilateral mastectomy, having mental or cognitive problems that would preclude questionnaire completion, not being able to speak English, and inability/unwillingness to give consent. The study team enrolled 227 women out of the 371 eligible patients who were invited to participate (61.1%). The large majority of participants (224, or 99.0%) were treated at Siteman Cancer Center.

Half of the women in the study were randomly assigned to receive a narrative intervention: a computer tablet loaded with video stories from African American breast cancer survivors. These stories covered a range of topics related to six themes: relationships/support, experience with health care, experience with follow-up care, quality of life, dealing with cancer, and side effects of treatment. Clips were chosen based on three criteria: likability, clarity/length,
and emotional impact. The development of this intervention has been described in more detail elsewhere (Pérez et al., 2014). Participants not in the invention group received usual care. All participants were interviewed via computer-assisted telephone interviews five times over two years about their quality of life, including health, relationships, and well-being. Baseline interviews (Time 1) occurred shortly after a patient’s post-operative visit or commencement of neoadjuvant therapy; subsequent interviews occurred approximately one month after baseline (Time 2), six months after definitive treatment surgery (Time 3), one year after definitive treatment surgery (Time 4), and two years after definitive treatment surgery (Time 5). Participant attrition was relatively low, with approximately 85% of participants retained through the final interview.

The specific aims for the original Survivor Stories Study focused on the effects of the narrative intervention on three types of outcomes: adherence to treatment, adherence to surveillance mammography, and quality of life. The current study did not focus on the effects of the narrative intervention; instead, the analyses accounted for the potential confounding effects of the intervention in models that analyzed the impact and dynamics of relationships and social support. The full Survivor Stories sample (N = 227) was made up of 107 people in the intervention group and 120 people in the control group. Based on the results from a series of difference tests (see below), these groups were combined for the growth curve analyses.

### 3.1.2 Sample for Aim 2

Data for Aim 2 came from a follow-up qualitative study of married women from the Survivor Stories Study. To explore how women perceived breast cancer to have affected their relationships and their partners, a qualitative study was conducted with 15 married women from the Survivor Stories Study sample. This study was intended to inform future quantitative, dyadic
research that investigates how a breast cancer diagnosis affects the health and well-being of both African American women and their partners.

Eligible women included Survivor Stories Study participants who were married at the time of their breast cancer diagnosis, who reported still being married to the same partner at the time of recruitment for the follow-up study, and who had agreed to be contacted for future research and have their data shared with other researchers. Restricting the interviews to married women in the Survivor Stories Study allowed exploration of how breast cancer affects stable relationships and also ensured a degree of homogeneity within the follow-up study group (Miles, Huberman, & Saldaña, 2014). A sample size of at least 10 is acceptable in qualitative research when such homogeneous sampling is used (Sandelowski, 1995), and, to be conservative, the recruitment target for the follow-up study was set at 50% more than that (i.e., 15 participants). The intention was to achieve saturation, which means that all relevant themes were expected to have emerged by the end of the last interviews (Sandelowski, 1995, p. 182). After coding was complete, both coders believed that saturation had been achieved for the major themes.

Married women were selected as the population for the follow-up study for several reasons: 1) This study was intended to inform future dyadic research, and such analyses generally require stable relationships. 2) Although it may also be informative to interview women who changed relationship status since beginning the study, that group was quite small. Unpublished analysis of data from a study of White and African American breast cancer patients in the St. Louis area (Jeffe et al., 2012) showed that only 3% of participants changed relationship status over a two-year period. In the current sample at 2-year follow-up, 90% of the women who were still enrolled in the study maintained the same relationship status as they had had at baseline. Given the focus on stable relationships, it would also have been difficult to administer
some of the close-ended and open-ended items to people who were no longer in a relationship with their partner from the time of diagnosis. 3) Analysis of baseline study data revealed that only 3 people (< 2% of the study sample) reported being in unmarried partnerships; given the potential differences in health and well-being between people who are married and cohabiting (Cherlin, 2009; Marcussen, 2005; Brown, 2000), it made sense to choose one group or the other, and the married group was larger. In short, although there are strong conceptual reasons to study a range of relationships, this small, exploratory study focused on analyzing women who had been continuously married throughout diagnosis and treatment.

Participants were recruited from August to October 2015 from those women in the larger Survivor Stories Study sample who met all inclusion criteria for the follow-up study (N = 46, with 29 in the control arm and 15 in the intervention arm). Women who met criteria were mailed a consent form and a recruitment letter inviting them to participate in a follow-up interview. The author contacted participants via telephone to assess eligibility and interest in participation, answer any study-related questions, and schedule in-person interviews for those wishing to participate. Letters were mailed to all 46 women who were eligible for the follow-up study, and phone contact was attempted with all of them. Of these, 15 consented to participate (4 from the intervention arm and 11 from the control arm), 19 were unable to be reached or did not respond to phone messages, and 12 were reached via telephone and refused to participate. All 15 of the women had received treatment at Siteman Cancer Center.

The consent process took place immediately prior to the interview. Interviews, which lasted approximately one hour, were conducted and audio recorded by the author in a private room at 600 S. Taylor Avenue, the building that houses the Institute for Public Health at Washington University School of Medicine.
3.2 Measurement of Key Constructs

3.2.1 Aim 1

Aim 1 was designed to examine how perceived social support changes over time and analyze the predictors and effects of such change. Predictor variables included those suggested by the literature as relating to social support, including marital status (Aizer et al., 2013), depressive symptoms (Patten, Williams, Lavorato, & Bulloch, 2010), income (Mickelson & Kubzansky, 2003), and age (Sammarco, 2009; Schroevers, Helgeson, Sanderman, & Ranchor, 2010). Cancer-related variables and additional demographic variables were included as control variables. A measure of religiosity was included in the analyses because many participants in the qualitative interviews (which were being conducted concurrently with the quantitative analyses) discussed the importance of religion in their lives and in their adjustment to cancer.

Social Support

The Medical Outcomes Study Social Support Survey (MOS-SS; Sherbourne & Stewart, 1991) was used to measure perceived social support. The MOS-SS assesses information about positive dimensions of social support. Participants are asked “How often is each of the following kinds of support available to you if you need it?” for 19 items (e.g., “Someone to help you if you were confined to bed,” or “Someone who understands your problems”). The 5-point Likert-type response options range from 0 (none of the time) to 5 (all of the time). The mean of the 19 items can be transformed into a standardized score that ranges from 0 to 100, with higher scores indicating greater social support (RAND Corporation, 2014).

The MOS-SS was developed using data from a relatively diverse population of people receiving treatment for chronic disease (20% nonwhite, age range 18-98, with a mean 13.3 years of education) and demonstrated good convergent and discriminant validity in the original sample.
(Sherbourne & Stewart, 1991). The creators of the MOS-SS found that the scale demonstrated very high internal consistency (α = .97 for the total scale) and that scores were most strongly correlated with measures of loneliness (r = -.67), family functioning (r = .53) and marital functioning (r = .56) (Sherbourne & Stewart, 1991). The MOS-SS contains four subscales: emotional/informational support, tangible support, affectionate support, and positive social interaction. Because a prior unpublished confirmatory factor analysis of MOS-SS subscales in St. Louis-area breast cancer patients found little support for a four-factor model with distinct subscales (Thompson, 2013), the scale was used in its entirety as a global measure of perceived social support.

The MOS-SS was developed to measure perceived social support in community-dwelling adults with a range of chronic diseases (McDowell, 2006), and it has been used in African American research samples (e.g., Brittain et al., 2012; Compton, Thompson, & Kaslow, 2005) and in research involving diverse samples of breast cancer patients (Ashing-Giwa & Rosales, 2013; Jeffe et al., 2012; Giedzinska et al., 2004; Ganz et al., 2002). Ashing-Giwa and Rosales (2013) reviewed reliability and validity of the MOS-SS as reported in published studies with diverse samples of cancer patients and found that, although reliability was consistently high (α ≥ .84, with α = .96 among African Americans in their own sample), no studies included information about validity in diverse populations. The authors found a moderate correlation (r = .52) between the MOS-SS and the social/family subscale of the Functional Assessment of Cancer Therapy-General (FACT-G) scale (Ashing-Giwa & Rosales, 2013). In the current sample, Cronbach’s α was > .96 at every time point.

**Relationship Status**
Participants chose from the following mutually exclusive options to describe their relationships status: married, divorced, widowed, separated, never married, or a member of an unmarried couple. Because same-sex marriage was not legal in Missouri during the time participants were recruited into the study, it was assumed that people who reported being married were in heterosexual relationships. As in prior research (Thompson et al., 2013), relationship status was collapsed into a binary variable (1 = currently married/partnered, 0 = not currently married partnered) for the growth curve analyses. In the entire sample at baseline, 26.9% of participants were married, 26.0% were divorced, 8.4% were separated, 14.1% were widowed, 23.3% had never been married, and 1.3% were a member of an unmarried couple. Because this question was asked at every time point, changes in relationship status over time could also be assessed.

**Depressive Symptoms**

Depressive symptoms were measured using the Center for Epidemiologic Studies Depression Scale (CES-D, Radloff, 1977), which has been widely used in both research and clinical practice (McDowell, 2006). The CES-D assesses depressive symptoms over the past 7 days and yields scores that range from 0 to 60, with higher scores indicating greater depressive symptoms; a cutoff of ≥ 16 is often used to indicate elevated depressive symptoms. The CES-D has shown good construct and concurrent validity and has demonstrated reliability in a range of populations, including psychiatric populations, people of varied racial backgrounds, and people of a range of socioeconomic statuses (Ashing-Giwa & Rosales, 2013; Catz, Gore-Felton, & McClure, 2002; Radloff, 1977). Studies with diverse samples of cancer patients have found good reliability (Ashing-Giwa & Rosales, 2013, for example, report α = .88 among African Americans in their own sample and a range of .87 to .91 in other published studies), and multiple
studies have found that the CES-D is correlated with other measures of mental health and positive/negative affect (Ashing-Giwa & Rosales, 2013). An assessment of the CES-D in cancer patients concluded that scores above recommended cutoffs were strongly correlated with structured clinical interview diagnosis of depression and noted that the instrument was feasible to administer to patients to assess depressive symptoms due to the measures’ length, simplicity, and strong psychometric properties (Hopko et al., 2007). Another advantage to using the CES-D is that its widespread use facilitates comparisons across studies. It is important to keep in mind, however, that the CES-D assesses depressive symptoms but does not necessarily reflect a diagnosis of depression. In this sample, Cronbach’s α for the CES-D was .92 at baseline.

**General Health**

General health was assessed using the General Health Subscale of the Medical Outcomes Study Short Form Health Survey (MOS SF-36, also referred to as the RAND 36-Item Health Survey; McHorney, Ware, Lu, & Sherbourne, 1994; Ware & Sherbourne, 1992). Higher scores indicate better health perceptions. Described as “the leading general health measure” (McDowell, 2006, p. 119), the MOS SF-36 was developed for use in a clinical population based on data from patients in three cities (20% nonwhite, 7% in poverty) and has been found to be reliable and valid in diverse populations (Wolinsky, Miller, Andresen, Malmstrom, & Miller, 2004; Peek et al., 2004; Johnson et al., 1995). The scale has been used for research purposes in diverse samples of women with breast cancer (Jeffe et al., 2012; Ganz et al., 2002; Ashing-Giwa, Ganz, & Petersen, 1999).

The MOS SF-36 contains eight subscales (physical functioning, role limitations due to physical health, role limitations due to emotional problems, fatigue, emotional well-being, social functioning, pain, and general health) that are often used individually. The five-item general
health subscale measures both physical and mental components of health, although validity tests have shown it is more strongly associated with physical health than with mental health (McDowell, 2006; McHorney, Ware, & Raczek, 1993). Ashing-Giwa and Rosales (2013) found acceptable internal consistency ($\alpha = .78$) in the health subscale among African American breast cancer survivors. Another study of the SF-36 in a much larger African American sample ($N = 998$ men and women ages 49 to 65) confirmed the original factor structure reported by the developers of the SF-36 and found that all of the subscales displayed sound psychometric properties (including reliability of $\alpha = .80$ for the health subscale) (Wolinsky et al., 2004). The authors concluded that the general health subscale is reliable and valid for measuring health among middle-aged African Americans (Wolinsky et al., 2004). In this sample, Cronbach’s $\alpha$ for the general health subscale was .75 at baseline.

**Religious and Spiritual Beliefs**

Religious and spiritual beliefs and practices were measured by the Systems of Belief Inventory (SBI; Holland et al. 1998), a scale assessing religious behaviors as well as spiritual aspects of coping that was designed to be used with individuals reporting a range of religious affiliations, including those who are atheist, agnostic, or without religious affiliation. The scale, which consists of 15 items with Likert-type response options ranging from 0 (*strongly disagree*) to 3 (*strongly agree*), yields scores ranging from 0 to 45, with higher scores indicating greater religiosity/spirituality. There are two subscales measuring social support from a religious community (5 items) and religious beliefs and practices (10 items). The creators of the SBI reported good psychometric properties in both healthy samples and samples of people facing serious illness (Holland et al., 1998). In their initial assessment in a sample that was healthy, highly educated, and predominantly White, the scale demonstrated excellent internal reliability
(Cronbach’s $\alpha = .93$), convergent validity with other measures of religiosity and spirituality, and divergent validity from general quality of life measures such as the MOS SF-36 (Holland et al., 1998). A study in a sample of cancer patients found evidence for convergent validity between the SBI and the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp) (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002). The SBI has been used in a variety of populations, including African Americans with diabetes (Watkins et al., 2013), women with breast cancer (Kornblith et al., 2001), women with ovarian cancer (Canada et al., 2006), and a racially diverse sample of childhood cancer survivors (Stolley et al., 2009).

In the current sample, Cronbach’s $\alpha$ for the SBI was .88 at baseline. The SBI, as well as its social support subscale, was assessed for correlation with the MOS-SS to determine the degree of overlap between the two. At baseline, there was only moderate correlation between the overall SBI and the MOS-SS ($r = .33$). In addition, there was only moderate correlation between the MOS-SS and the SBI social support subscale ($r = .34$).

**Other Demographic and Clinical Variables**

Demographic variables were based on participant-self report and were intended for use as control variables in the original analyses. These included employment status (working part-time versus not), level of education (grades 1-8; grades 9-11; high school diploma/equivalent; 1-3 years college; 4+ years of college), and household income (6 categories ranging from < $10,000 to > $100,000). Age was measured continuously in years and calculated using participants’ birth dates. Comorbidity of other chronic conditions was assessed based on self-report using an adapted version (Katz, Chang, Sangha, Fossel, & Bates, 1996) of the Charlson comorbidity index (Charlson, Pompei, Alex, & MacKenzie, 1987), which derives a weighted score (range 0 - 31) based on the number and severity of comorbid conditions. Cancer stage was determined by
clinical staging; treatment information and receipt of two-year surveillance mammography were determined based on both self-report and the medical record. Participants were counted as having received two-year surveillance mammography if mammograms were verified by the medical record.

3.2.2 Aim 2

Although the follow-up study was primarily qualitative, quantitative data from the main Survivor Stories Study and the follow-up interview were used to create descriptive statistics for the sample. Constructs including social support, depressive symptoms, spirituality, and general health were measured as described above and presented for the follow-up study sample.

Relationship history, family structure, partner characteristics, and relationship quality were assessed as follows:

Relationship and Family Questions

Participants were asked the duration of their marriage in years, as well as the total number times they and their partner had each been married. In addition, they were asked about how their spouses identified their own race/ethnicity. Participants were asked whether they had children with their spouse and, if so, how many.

Relationship Adjustment

For the qualitative study, relationship adjustment was measured using the seven-item Dyadic Adjustment Scale (DAS-7; Hunsley, Best, Lefebvre, & Vito, 2001). The DAS-7, a brief version of the 32-item Dyadic Adjustment Scale (Spanier, 1976), contains seven items. (For example, “Please indicate below the approximate extent of agreement or disagreement between you and your partner about amount of time spent together.”) Likert-type response options for the first six items range from 0 to 5, and the response to the final item assessing global happiness in
the relationship ranges from 0 to 6. DAS-7 scores can range from 0 to 36, with higher scores indicating better relationship adjustment. A score of under 21 is indicative of marital distress (Badr & Shen, 2014). Hunsley et al. (2001) found that the DAS-7 demonstrated good internal consistency (Cronbach’s α .75-.80), as well as the ability to discriminate between couples in the general population and those who had sought marital therapy. Other studies have also found good internal consistency (Cronbach’s α .84 -.87) for the DAS-7 (Badr & Shen, 2014; Owen, Antle, & Barbee, 2013).

The DAS-7 has been used to assess relationship quality in a range of settings, including a predominantly African American sample of participants in a relationship education program (Owen, Antle, & Barbee, 2013), a predominantly White sample of women with metastatic breast cancer (Badr & Shen, 2014), and an entirely African American sample of breast cancer survivors (Schover et al., 2006). In the current sample, Cronbach’s α for the DAS-7 was .87.

Interview Guide

Qualitative data was gathered using open-ended questions (Appendix A). In qualitative studies, the amount of prior instrumentation (or decisions about how data will be collected in advance) can vary a great deal and should be based on the nature of the study (Miles et al., 2014). This study used an interview guide that was created based on the literature about social support and intimate partnerships. The goal was to elicit in-depth responses about participants’ relationships with spouses and how participants perceive their cancer diagnosis to have affected their spouses.

The initial question allowed participants to reflect on their relationship with their partner prior to their diagnosis of breast cancer. The second question asked participants to reflect on how they thought cancer changed their relationship. Because the MOS-SS does not differentiate
between social support received from intimate partners versus other people, several open-ended questions were designed to gather more information about specific kinds of support received or desired from spouses and others. Because past research has demonstrated the interrelationship between mental and physical health between cancer patients and their intimate partners (e.g., Kim et al., 2015; Valle et al., 2013; Dorros et al., 2010), two questions addressed whether participants perceive their diagnosis to have affected partners’ mental and physical health. Given prior research about the importance of accounting for comorbid conditions (Berg et al., 2011; Hagedoorn et al., 2008), one question addressed other health conditions and life stressors in addition to cancer. The two final questions (what participants would want a woman recently diagnosed with breast cancer to know about how cancer affects relationships, and how doctors and other clinicians can help couples face cancer together) were designed to allow participants to summarize their thoughts and add any additional information about the effect of cancer on relationships not already addressed by interview questions. This was especially important because participants often interpret and create meaning as they respond to open-ended questions in qualitative interviews (Miles et al., 2014), and the two broad final questions gave them the opportunity to share any new interpretations they may have generated over the course of the interview.
3.3 Analysis Plan for Aim 1

A range of modeling techniques were used to explore the data and test hypotheses for Aim 1. Analytic techniques are briefly described here and then tied to specific hypotheses below. In addition to descriptive statistics, bivariate tests, and multivariable linear regression techniques (Cohen, Cohen, West, & Aiken, 2003), analyses included growth curve models (also known as latent trajectory models or latent curve models). This technique is a form of structural equation modeling that requires three or more waves of data and allows researchers to differentiate between a construct’s systematic change over time (i.e., the slope) and the estimated initial level of a construct (i.e., the intercept) (Curran & Hussong, 2003). Described as “essentially a multilevel model for change” (Singer & Willett, 2003), a growth curve model provides a flexible means of estimating change or growth over time. These models can take a variety of forms, including unconditional models (in which only the repeated measures are analyzed) and conditional models (in which other variables are used to predict change in a repeated measure over time) (Bollen & Curran, 2006). As Curran, Obeidat, and Losardo (2010) explain, the term growth curve modeling encompasses models with a range of uses: “In many applications, the trajectories [of growth or change] are the primary focus of analysis, whereas in others, they may represent just one part of a much broader longitudinal model” (p. 123). Growth curve models were used to test Hypotheses 1-3 (described below).

Unlike traditional methods such as repeated-measures analysis of variance (ANOVA), growth curve models offer improved statistical power and can handle unevenly spaced time points (Curran et al., 2010). Figure 2 depicts a general growth-curve model that involves MOS-SS scores at five time points. Such models can handle data that are not normally distributed, which is an important consideration because prior analyses in a sample of breast cancer survivors
and controls found that MOS-SS scores were not normally distributed (Thompson et al., 2013). Although Curran et al. (2010) report that growth curve models have been successfully used with sample sizes as low as 22, the authors state that “sample sizes approaching at least 100 are often preferred” (p. 125).

Because the Survivor Stories Study involved two groups (the intervention group and the group that received usual care), and because the intervention was hypothesized to affect social support, two types of models were tested: a two-group model and a one-group model that controlled for group status. Using multiple-group models allows parameters to differ between groups when necessary instead of assuming they are invariant (Curran et al., 2010), but if the parameters are similar between groups a one-group model that controls for group status may be preferable due to additional power. Differences between a one-group and a two-group model were examined using a series of difference tests as described by Bollen and Curran (2006, p. 171). These tests suggested that a linear model was a good fit for both groups and that intercepts, slopes, and variances were not significantly different across groups. For that reason, all growth curve models used a one-group model that controlled for study group.

Descriptive analyses and bivariate analyses were performed in IBM SPSS Statistics 22 (Armonk, NY). Mplus version 7.1 (Muthén & Muthén, 1998-2012) was used for analyses involving structural equation modeling. Mplus has the advantage of including multiple estimators that can handle continuous or binary outcome variables, multiple data sets from multiple imputation, and missing or non-normally distributed data. The current analyses were conducted using the MLR estimator, which provides maximum likelihood estimation with robust standard errors. Model fit for growth curve models was assessed with a variety of fit indices (Curran et al., 2010): a model chi-square test (with $p < .05$ the level for significance) using the
Satorra-Bentler statistic to correct for non-normality (Klein, 2011); the Tucker-Lewis incremental fit index (TLI) (Tucker & Lewis, 1973); the comparative fit index (CFI) (Bentler, 1990); the root mean square error of approximation (RMSEA) (Steiger & Lind, 1980); and the standardized root mean square residual (SRMR) (Jöreskog & Sörbom, 1981; Bentler, 1995). Values of .90 and higher are considered acceptable for the TLI and CFI. Values of .08 or lower are considered acceptable for the RMSEA and SRMR (Hu & Bentler, 1999).

3.3.1 Missing Data
Missing data for all variables were handled with multiple imputation (Allison, 2009). A set of 10 imputed datasets was created in Amelia II (Honaker, King, & Blackwell, 2012), and the MLR estimator in Mplus estimated model results that were averaged across all datasets. Diagnostic tests indicated successful imputation of missing values (Honaker, King, & Blackwell, 2012).

The question sometimes arises about whether to impute values for a dependent variable Allison (2009). The growth curve models used to test Hypotheses 1 and 2 do not have dependent variables in the traditional sense, but the models used to test Hypothesis 3 do. Allison (2009) recommends imputing the dependent variable only if there are “auxiliary variables” included in the imputation that are correlated with the dependent variable but not included in the models. For the two outcome variables with missing data (depression at Time 5 and general health at Time 5), there were significantly correlated variables that were used for imputation but not included in those models; therefore, the outcome variables were imputed. All participants had a value for the two-year mammography variable, and thus no imputation was used.

Over the course of follow up, nine participants died. There is currently no consensus about how to handle attrition due to death in longitudinal quality of life studies, but the most
common method is to delete those cases (Biering, Hjollund, Frydenberg, 2015). In the current study, models were run both with and without participants who died during follow up; the significance of model parameters was identical, with one exception (noted below). Results are presented here for models in which the cases of deceased participants were excluded, with a final sample size of 218.

3.3.2 Tests for Individual Hypotheses
The following statistical methods were used for individual hypotheses.

**Hypothesis 1: Perceived social support will decline significantly over time.** A growth curve model (Model 1) was used to determine whether social support changed significantly over time and whether there was significant variability between participants in changes in social support. In this unconditional model (Bollen & Curran, 2006), the only variables were MOS-SS scores at each time point (Figure 2). This follows the suggestion of Kline (2011; p. 305-306) that growth curve models be analyzed in two steps: 1) A model containing only the repeated measures variables in order to look for significant change, and 2) A model that includes predictors to explain such change (see Hypothesis 2 below). A significant mean slope would indicate that the entire sample on average demonstrated systematic change in social support over time. Significant variability in social support slope would indicate that there was between-participant variability in social support trajectories that was not captured solely by examining mean social support scores (Bollen & Curran, 2006). In all growth curve models, the significance level was set at $p < .05$. 
Figure 2 Unconditional model of perceived social support. Intercept and slope are modeled as latent variables that influence observed social support scores at all time points. (All growth curve figures adapted from Thompson et al., 2013.)

Hypothesis 2: Individuals’ change in social support over time (slope) and stable levels of social support (intercept) will be predicted by psychosocial variables (depressive symptoms and religiosity), demographic variables (relationship status, income, education, age, insurance status, and employment status), health variables (self-reported general health, and comorbidity), and cancer-related variables (stage and treatment type). In this next step of model specification (Kline, 2011; Bollen & Curran, 2006), a growth curve model with the predictors listed above (Model 2) was used to test this hypothesis. In this conditional model (Bollen & Curran, 2006), the slope and intercept were treated as outcomes that were predicted by other variables (Figure 3). That is, the model was designed to determine whether the predictors were significantly associated with either the estimated starting point of social support.
support (intercept) or systematic change in social support over time (slope). Even if the sample as a whole did not demonstrate a change in mean social support scores over time, if there was significant variability in social support trajectories between individuals, this model could be used to assess whether the variables in the model help predict which individuals increased or decreased in their social support over time. The model also could be used to assess whether those same variables affect individuals’ estimated starting point of social support.

Figure 3 Conditional model (Model 2) in which Time 1 variables are modeled as influencing the latent variables of social support slope and intercept.

Hypothesis 3: Greater decline in social support and lower social support intercept will be associated with lower general health, higher levels of depressive symptoms, and less likelihood of surveillance mammography at two-year follow-up (controlling for levels of health and depressive symptoms at baseline). To test this hypothesis, three models were created using the latent factors of social support slope and intercept similar to those estimated in
the analyses for Hypothesis 2. These models included slope and intercept as *predictors* of
general health at two years, level of depressive symptoms at two years, and likelihood of two-
year surveillance mammography, respectively (Figure 4). All models controlled for study arm.
To establish temporal order between the predictors and the outcome, the models estimated slope
and intercept based on social support scores from the first four time points only. The model of
general health controlled for general health at baseline, and the model of depressive symptoms
controlled for depressive symptoms at baseline. The dataset contained no baseline measure of
screening mammography use, and thus the surveillance mammography model did not include a
control variable from baseline. Women who were not eligible for surveillance mammography at
two years due to death or bilateral mastectomy were excluded from that analysis, with a final N =
207.
Figure 4 General figure illustrating Models 3-5. The latent variables of social support slope and intercept, estimated from the first four time points, are used to predict depressive symptoms, general health, and surveillance mammography at two years. Not shown are controls for study arm and baseline health and depressive symptoms.

3.4 Analysis Plan for Aim 2

Qualitative research can be a valuable method for understanding how people create and interpret their social reality (Cohen & Crabtree, 2006; Miles et al., 2014). Such research can be used as an additional method of collecting information (e.g., in a mixed methods study) or allow for an inductive, in-depth approach to analysis in which observed data lead to new insights and theories. In-depth interviews can be used to collect information and generate hypotheses about understudied populations (e.g., Reczek & Umberson, 2012). In the qualitative follow-up study, such interviews explored how participants believed breast cancer diagnosis and treatment affected their relationships with their spouses, as well as their spouses’ health and well-being.
Techniques from grounded theory were used to conduct a thematic analysis of the qualitative interviews (Cohen & Crabtree, 2006). Analysis of transcribed responses to open-ended questions, conducted using Dedoose Version 6.2.17 (Los Angeles, CA: SocioCultural Research Consultants, LLC, www.dedoose.com, 2015), was systematic and iterative. After each interview, the interviewer prepared a summary of the interview and identified any important issues to be explored in subsequent interviews. Interviews were audio recorded by the study coordinator and professionally transcribed by Landmark Associates. The study coordinator verified all transcripts against the recordings for accuracy.

The process of coding is a crucial part of analyzing qualitative data (Miles et al., 2014): “Codes are primarily… used to retrieve and categorize similar data chunks so the researcher can quickly find, pull out, and cluster the segments relating to a particular research question, hypothesis, construct, or theme” (Miles et al., 2014, p. 72). Coding was conducted by two trained coders in stages and involved both deductive and inductive processes (Miles et al., 2014). First, the study coordinator generated a preliminary codebook that listed and defined codes about relationships, social support, and cancer suggested by the literature (i.e., deductive coding; Miles et al., 2014; p. 81). Next, the study coordinator conducted an initial review of transcripts and refined the codebook, adding codes that emerged from the transcripts; further additions to the codebook were made in consultation with the second coder (i.e., inductive coding; Miles et al., 2014, p. 81). Finally, both coders coded all transcripts independently using the final codebook (Appendix B) and Dedoose coding software. Coders then discussed any disagreement in coding in order to reach consensus (Padgett, 2012). It was determined in advance that, for any cases in which consensus could not be reached, the coders would consult with the Survivor Stories Study
principal investigator (Dr. Jeffe), who would make the final decision; however, both coders were able to achieve consensus on the coding of all transcripts.

Memos were prepared to analyze instances of individual codes, and Dedoose software was used to generate a code matrix that examined co-occurring codes. The author then used this information to generate memos examining recurring themes that spanned codes and analyze how such themes were similar or different across participants (i.e., *pattern coding*; Miles et al., 2014, p. 86). These broad themes were then discussed with the second coder. In addition, descriptive data about participants in the follow-up study sample was obtained from quantitative data collected during the parent study, as well as close-ended items from the interview guide. It should be noted that the small sample size meant the follow-up study was not powered for inferential analysis of data. Miles et al. (2014) note, however, that such linkages of qualitative and quantitative data can be “a very powerful mix” (p. 43) that allows researchers to describe and explore multiple kinds of data.

### 3.5 Protections of Human Subjects and Privacy

This research met all regulatory requirements at Washington University in St. Louis. The original Survivor Stories Study was approved by the Human Research Protection Office (HRPO) at Washington University and the Protocol Review and Monitoring Committee (PRMC) at Siteman Cancer Center. Data analysis for Aim 1 is covered under HRPO and PRMC approval for study #201102380. An amendment to the original Survivor Stories protocol covering Aim 2 was approved by HRPO on 2/12/15 and the PRMC on 3/4/15.

All participants in the original study gave informed consent and were paid $25 per telephone interview. Participants in the follow-up study went through the informed consent process with the follow-up study coordinator immediately prior to their interviews and were
given a chance to ask additional questions about the study before the interview began. Participants in the follow-up study were paid $35 and, if applicable, received vouchers to reimburse them for parking costs. After the first participant completed the qualitative study, a referral procedure to university counseling resources was put in place for participants who seemed to be experiencing extensive distress in their daily lives; three participants were given such referrals.

Privacy of study participants was carefully protected. All electronic files containing study data were stored on password-protected computers, encrypted storage devices, or the secure Washington University Cloud. Participants were identified only by study identification numbers. The list linking participants’ identifying information to study identification numbers was stored separately from other study data in a password-protected electronic file on a secure server and could only be accessed by members of the study team. Paper copies of close-ended survey questions, consent forms, and identifying information used for recruitment and participant payment were stored in a locked filing cabinet in a locked office/suite in the Division of General Medical Sciences. Names and any other identifying and HIPAA-protected information were redacted from transcripts of qualitative interviews, which were identified by study ID numbers only. After interviews were transcribed, the audio recordings, identified only by date of interview and ID number, were stored in encrypted files and a locked filing cabinet in the locked suite that houses the Division of General Medical Sciences at Washington University School of Medicine.
Chapter 4: Results

This chapter provides results for Aim 1 (quantitative analyses) and Aim 2 (qualitative analyses).

4.1 Results of Quantitative Analyses

Table 1 provides descriptive statistics for the entire Survivor Stories sample. At baseline, 28.2% of participants were married/partnered. Mean age was 56.0 ($SD = 10.0$) and most participants reported annual household income below $25,000. The majority of patients had early-stage cancer and were treated with breast-conserving therapy. The mean MOS-SS score was 81.9 ($SD = 19.8$).

Additional descriptive and bivariate analyses were conducted. Table 2 provides the mean scores for continuous variables at all time points. Table 3 provides bivariate Spearman correlations for all cancer-related variables. Appendix C provides further item-by-item information about the MOS-SS.
Table 1 Characteristics of African American women with breast cancer in the Survivor Stories Study (N = 227).

<table>
<thead>
<tr>
<th>Categorical variables</th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married/partnered</td>
<td>28.2% (64)</td>
</tr>
<tr>
<td>Private insurance</td>
<td>45.7% (101)</td>
</tr>
<tr>
<td>Working at least part-time</td>
<td>44.1% (100)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>&lt;12th grade</td>
<td>16.7% (38)</td>
</tr>
<tr>
<td>12th grade/equivalent</td>
<td>30.8% (70)</td>
</tr>
<tr>
<td>&gt;12th grade</td>
<td>52.4% (119)</td>
</tr>
<tr>
<td>Household income</td>
<td></td>
</tr>
<tr>
<td>&lt;$25,000</td>
<td>59% (131)</td>
</tr>
<tr>
<td>$25,000-$74,999</td>
<td>33.3% (74)</td>
</tr>
<tr>
<td>≥ $75,000</td>
<td>7.7% (17)</td>
</tr>
<tr>
<td>Cancer stage</td>
<td></td>
</tr>
<tr>
<td>Early</td>
<td>72.2% (164)</td>
</tr>
<tr>
<td>Late</td>
<td>27.8% (63)</td>
</tr>
<tr>
<td>Surgery type</td>
<td></td>
</tr>
<tr>
<td>Breast conserving surgery</td>
<td>69.2% (155)</td>
</tr>
<tr>
<td>Mastectomy</td>
<td>30.8% (69)</td>
</tr>
<tr>
<td>Hormone therapy</td>
<td>63.1% (142)</td>
</tr>
<tr>
<td>Radiation therapy</td>
<td>77.4% (175)</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>49.6% (112)</td>
</tr>
<tr>
<td>Had two-year mammogram</td>
<td>86.5% (179)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Continuous variables</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>56.0 (10.0)</td>
</tr>
<tr>
<td>MOS-SS score</td>
<td>81.9 (19.8)</td>
</tr>
<tr>
<td>CES-D score</td>
<td>11.9 (11.4)</td>
</tr>
<tr>
<td>SBI score</td>
<td>40.5 (5.8)</td>
</tr>
<tr>
<td>RAND general health</td>
<td>59.1 (22.4)</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>1.01 (1.4)</td>
</tr>
</tbody>
</table>

Note: At baseline, data were missing as follows: insurance (6 participants), income (5), surgery type (3), hormone therapy (2), radiation therapy (1), chemotherapy (1), and SBI score (1). A total of 207 women were eligible for two-year mammography. MOS-SS = Medical Outcomes Study Social Support Survey; CES-D = Center for Epidemiologic Studies Depression scale, SBI = Systems of Belief Inventory.
Table 2 Mean (SD) for continuous variables at all time points.

<table>
<thead>
<tr>
<th></th>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 3</th>
<th>Time 4</th>
<th>Time 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Outcomes Study Social Support Survey (standardized score)</td>
<td>81.9 (19.8)</td>
<td>82.5 (19.3)</td>
<td>81.0 (21.5)</td>
<td>81.8 (21.4)</td>
<td>80.0 (20.9)</td>
</tr>
<tr>
<td>Center for Epidemiologic Studies Depression Scale</td>
<td>11.9 (11.4)</td>
<td>12.0 (11.7)</td>
<td>12.2 (12.7)</td>
<td>11.2 (12.0)</td>
<td>11.1 (12.1)</td>
</tr>
<tr>
<td>General health (Medical Outcomes Study Short Form-36 subscale)</td>
<td>59.1 (22.4)</td>
<td>58.4 (21.0)</td>
<td>57.1 (22.0)</td>
<td>57.5 (23.2)</td>
<td>54.7 (22.9)</td>
</tr>
<tr>
<td>Comorbid conditions</td>
<td>1.0 (1.4)</td>
<td>1.0 (1.4)</td>
<td>.56 (.9)</td>
<td>.58 (.9)</td>
<td>.64 (1.1)</td>
</tr>
<tr>
<td>Systems of Belief Inventory</td>
<td>40.5 (5.8)</td>
<td>40.5 (6.1)</td>
<td>39.9 (7.2)</td>
<td>40.6 (6.0)</td>
<td>40.8 (7.1)</td>
</tr>
</tbody>
</table>
Table 3 Spearman correlations for cancer-related variables in 227 African American breast cancer patients in Survivor Stories.

<table>
<thead>
<tr>
<th></th>
<th>Stage (1 = late)</th>
<th>Surgery (1 = mastectomy)</th>
<th>Radiation therapy (1 = yes)</th>
<th>Hormone therapy (1 = yes)</th>
<th>Chemotherapy (1 = yes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage (1 = late)</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery (1 = mastectomy)</td>
<td>.281*</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiation therapy (1 = yes)</td>
<td>.136</td>
<td>-.494*</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hormone therapy (1 = yes)</td>
<td>.046</td>
<td>-.09</td>
<td>.114</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Chemotherapy (1 = yes)</td>
<td>.529</td>
<td>.086</td>
<td>.239*</td>
<td>-.086</td>
<td>1</td>
</tr>
</tbody>
</table>

Note: Data were missing as follows: surgery type (3), hormone therapy (2), radiation therapy (1), and chemotherapy (1).

*p < .05

A series of growth curve models was used to test the three hypotheses for the quantitative study.

4.1.1 Hypothesis 1

Hypothesis 1, that perceived social support would decline significantly over time, was not supported. Model 1, a one-group unconditional model that controlled for study arm, was fit to the repeated measures social support data. This model demonstrated excellent fit according to the criteria described in Chapter 3 ($\chi^2(10) = 12.60$, RMSEA = .03, CFI = .99, TLI = .99, SRMR = .05). The mean intercept of social support was significantly different from zero (mean intercept = 81.87, $p < .001$), but the mean slope was not significantly different from zero,
indicating no significant change in average levels of social support over time (mean slope = - .106, \( p = .773 \)). There was, however, significant variability in both stable levels of social support and change in social support among participants (\( p < .001 \)), indicating that individuals had varied trajectories that were not fully described by mean scores. Figure 5 shows this variability in social support. Among all participants, approximately 33% had a slope of < -1 (indicating MOS-SS standardized scores increased by approximately four or more points over the course of the study); 38% had a social support slope between -1 and 1 (indicating their MOS-SS score was roughly stable); and 29% had slope > 1 (indicating their MOS-SS standardized scores went up approximately four or more points over the course of the study). It should be noted that these cutoffs are not based on clinical thresholds and are provided only to help readers conceptualize changes in social support over time in the sample as a whole. In all growth curve models presented here, slope is a continuous variable.
Figure 5  Distribution of social support slope in Survivor Stories participants. Although mean slope for all participants was not significantly different from zero, there was significant variability in slope between participants.

Because the lack of change in mean social support over time was unexpected based on prior research conducted with early-stage breast cancer patients at this cancer center (Thompson et al., 2013), two post hoc tests were conducted to see whether the current findings might be influenced by the intervals between time points or the inclusion of late-stage patients. In the first test, the first time point was omitted to see whether results differed. In the second, a model was run with only early-stage patients. Neither model showed significant change in mean social support scores over time. A review of individual scale items by time point (Appendix C) showed that scores stayed relatively stable over time, and no item showed a change greater than .2 points between time points. In addition, descriptive statistics (Table 4) were used to compare the
income distribution for Survivor Stories participants and African American participants in the previous study (Thompson et al., 2013). The income distribution appeared to be largely similar across the two studies.

Table 4 Descriptive statistics for household income in participants in an early stage longitudinal breast cancer study (Thompson et al., 2013) and Survivor Stories.

<table>
<thead>
<tr>
<th>Household income</th>
<th>African American early stage breast cancer patients (N = 97)</th>
<th>Survivor Stories sample (N = 222)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; $10,000</td>
<td>32.4%</td>
<td>30.4%</td>
</tr>
<tr>
<td>$10,000 - $24,999</td>
<td>25.5%</td>
<td>27.3%</td>
</tr>
<tr>
<td>$25,000 - $49,999</td>
<td>23.5%</td>
<td>25.1%</td>
</tr>
<tr>
<td>$50,000 - $74,999</td>
<td>7.8%</td>
<td>7.5%</td>
</tr>
<tr>
<td>$75,000 - $99,999</td>
<td>3.9%</td>
<td>5.7%</td>
</tr>
<tr>
<td>$100,000 +</td>
<td>2.0%</td>
<td>1.8%</td>
</tr>
</tbody>
</table>

4.1.2 Hypothesis 2

Hypothesis 2, which stated that change in social support over time (slope) and stable levels of social support (intercept) would be predicted by psychosocial variables, health variables, demographic variables, and cancer-related variables, was partially supported. Table 5 shows results from Model 2, the conditional model that included predictors for intercept and slope. This model demonstrated good fit ($\chi^2(58) = 80.81$, RMSEA = .04, CFI = .96, TLI = .94, SRMR = .02), with the exception of a significant model chi-square statistic. It seemed likely that this indicator of poor fit was due to the large number of non-significant parameters in the model, and when the model was re-run with only significant or nearly significant variables (p < .10), the model chi-square was no longer significant.
In support of Hypothesis 2, several variables were associated with social support intercept. Being married/partnered was associated with higher stable levels of social support \( (p = .044) \). Higher scores on the Systems of Belief Inventory (SBI) were associated with higher stable levels of social support, and higher scores on the Center for Epidemiologic Studies Depression (CES-D) Scale were associated with lower stable levels of social support. Contrary to Hypothesis 2, variables related to physical health and cancer treatment were not associated with social support intercept, and none of the variables in the model predicted social support slope.

Because SBI score emerged as a significant predictor of social support intercept, and because the SBI contains a subscale the creators called “social support,” a post hoc analysis was conducted in which both SBI subscales replaced the overall SBI scale in Model 2. This was to determine whether the significant association between SBI score and MOS-SS intercept was due simply to the two scales’ measurement of the same construct (i.e., social support). In this model, neither SBI subscale was significant. This test, plus the fact that the correlation between the SBI social support subscale and the MOS-SS was only moderate, suggests that it was the overlap between the two subscales, and not simply the social support subscale, that was important in predicting stable levels of perceived social support.
Table 5 Results from Model 2 (conditional growth curve model) of predictors of social support intercept and slope in African American breast cancer patients (N = 218).

<table>
<thead>
<tr>
<th>Intercept predictors</th>
<th>Estimate</th>
<th>Standardized coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study arm (1 = intervention)</td>
<td>2.11</td>
<td>0.13</td>
</tr>
<tr>
<td>Married/partnered (1 = yes)</td>
<td>5.15*</td>
<td>0.33</td>
</tr>
<tr>
<td>Age</td>
<td>-0.03</td>
<td>-0.02</td>
</tr>
<tr>
<td>Working (1 = at least part time)</td>
<td>-3.17</td>
<td>-0.19</td>
</tr>
<tr>
<td>Education</td>
<td>-1.07</td>
<td>-0.07</td>
</tr>
<tr>
<td>Income</td>
<td>0.94</td>
<td>0.07</td>
</tr>
<tr>
<td>Insurance (1 = at least some private)</td>
<td>0.86</td>
<td>0.06</td>
</tr>
<tr>
<td>Late stage cancer (1 = late stage)</td>
<td>-5.08</td>
<td>0.05</td>
</tr>
<tr>
<td>Surgery type (1 = mastectomy)</td>
<td>0.80</td>
<td>0.13</td>
</tr>
<tr>
<td>Radiation therapy (1 = yes)</td>
<td>-0.87</td>
<td>-0.05</td>
</tr>
<tr>
<td>Chemotherapy (1 = yes)</td>
<td>4.40</td>
<td>0.27</td>
</tr>
<tr>
<td>Hormone therapy (1 = yes)</td>
<td>2.17</td>
<td>0.13</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>-0.59</td>
<td>-0.05</td>
</tr>
<tr>
<td>Depressive symptoms (CES-D)</td>
<td>-0.48*</td>
<td>-0.33</td>
</tr>
<tr>
<td>General health (SF-36 subscale)</td>
<td>-0.01</td>
<td>-0.02</td>
</tr>
<tr>
<td>Systems of Belief Inventory score</td>
<td>0.87*</td>
<td>0.31</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Slope predictors</th>
<th>Estimate</th>
<th>Standardized coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study arm (1 = intervention)</td>
<td>0.56</td>
<td>0.15</td>
</tr>
<tr>
<td>Married/partnered (1 = yes)</td>
<td>-0.01</td>
<td>-0.00</td>
</tr>
<tr>
<td>Age</td>
<td>-0.05</td>
<td>-0.14</td>
</tr>
<tr>
<td>Working (1 = at least part time)</td>
<td>0.22</td>
<td>0.06</td>
</tr>
<tr>
<td>Education</td>
<td>-0.67</td>
<td>-0.18</td>
</tr>
<tr>
<td>Income</td>
<td>-0.07</td>
<td>-0.02</td>
</tr>
<tr>
<td>Insurance (1 = at least some private)</td>
<td>1.24</td>
<td>0.33</td>
</tr>
<tr>
<td>Late stage cancer (1 = late stage)</td>
<td>0.31</td>
<td>0.08</td>
</tr>
<tr>
<td>Surgery type (1 = mastectomy)</td>
<td>-0.30</td>
<td>-0.08</td>
</tr>
<tr>
<td>Radiation therapy (1 = yes)</td>
<td>0.70</td>
<td>0.19</td>
</tr>
<tr>
<td>Chemotherapy (1 = yes)</td>
<td>0.39</td>
<td>0.10</td>
</tr>
<tr>
<td>Hormone therapy (1 = yes)</td>
<td>0.57</td>
<td>0.15</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>-0.20</td>
<td>-0.07</td>
</tr>
<tr>
<td>Depressive symptoms (CES-D)</td>
<td>-0.02</td>
<td>-0.07</td>
</tr>
<tr>
<td>General health (SF-36 subscale)</td>
<td>0.00</td>
<td>-0.00</td>
</tr>
<tr>
<td>Systems of Belief Inventory score</td>
<td>0.03</td>
<td>0.05</td>
</tr>
</tbody>
</table>

Note: The partially standardized coefficient is included for categorical variables, and the fully standardized coefficient is included for continuous variables. The coefficient for married/partnered was significant ($p = .044$) in the model in which patients who died over the course of the study were excluded (the results of which are presented here); the coefficient was nearly significant ($p = .066$) in the model that included those participants with imputed data. *$p < .05$
4.1.3 Hypothesis 3

Hypothesis 3, which stated that greater decline in social support and lower social support intercept would be associated with lower general health, higher levels of depressive symptoms, and lower likelihood of surveillance mammography at two-year follow-up (controlling for study arm and levels of health and depressive symptoms at baseline), was partially supported. Table 6 shows results from models predicting depressive symptoms (Model 3), general health (Model 4), and surveillance mammography (Model 5). Results from Model 3 indicated that both social support slope and intercept estimated from the first four time points were significantly associated with depressive symptoms at two years. Patients who had lower social support intercept and declines in social support over the first four time points were more likely to report higher levels of depressive symptoms at Time 5.

Results from Model 4 indicated that both social support slope and intercept estimated from the first four time points were significantly associated with general health at two years. People who had lower social support intercept and a decrease in social support over the first four time points were more likely to report lower levels of general health at Time 5. Results from Model 5 indicated that social support slope and intercept estimated from the first four time points were not associated with two-year surveillance mammography.
Table 6 Results from Models 3-5 using social support intercept and slope estimated across four time points to predict outcomes at Time 5 in African American breast cancer patients.

<table>
<thead>
<tr>
<th>Model 3: Depression (N = 218)</th>
<th>Estimate</th>
<th>Standardized coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social support intercept</td>
<td>-0.14*</td>
<td>-0.19</td>
</tr>
<tr>
<td>Social support slope</td>
<td>-1.05*</td>
<td>-0.39</td>
</tr>
<tr>
<td>Study arm (1 = intervention)</td>
<td>-1.57</td>
<td>-0.13</td>
</tr>
<tr>
<td>Depression (CES-D) at baseline</td>
<td>0.48*</td>
<td>0.46</td>
</tr>
</tbody>
</table>

Fit statistics: $\chi^2(14) = 13.77$, RMSEA = .01, CFI = 1.00, TLI = 1.00, SRMR = .04

<table>
<thead>
<tr>
<th>Model 4: General health (N = 218)</th>
<th>Estimate</th>
<th>Standardized coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social support intercept</td>
<td>0.30*</td>
<td>0.22</td>
</tr>
<tr>
<td>Social support slope</td>
<td>1.20*</td>
<td>0.25</td>
</tr>
<tr>
<td>Study arm (1 = intervention)</td>
<td>0.93</td>
<td>0.04</td>
</tr>
<tr>
<td>General health at baseline (SF-36 subscale)</td>
<td>0.57*</td>
<td>.56</td>
</tr>
</tbody>
</table>

Fit statistics: $\chi^2(14) = 12.05$, RMSEA = .00, CFI = 1.00, TLI = 1.01, SRMR = .04

<table>
<thead>
<tr>
<th>Model 5: Surveillance mammography (N = 207)</th>
<th>Estimate</th>
<th>Standardized coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social support intercept</td>
<td>0.01</td>
<td>0.09</td>
</tr>
<tr>
<td>Social support slope</td>
<td>0.03</td>
<td>0.08</td>
</tr>
<tr>
<td>Study arm (1 = intervention)</td>
<td>0.46</td>
<td>0.25</td>
</tr>
</tbody>
</table>

Fit statistics: $\text{AIC} = 7166.66$, $\text{BIC} = 7209.99$

**Note:** The partially standardized coefficient is included for categorical variables, and the fully standardized coefficient is included for continuous variables. RMSEA = root mean square error of approximation, CFI = comparative fit index, TLI = Tucker-Lewis incremental fit index, SRMR = standardized root mean square residual, AIC = Akaike Information Criterion, BIC = Bayesian Information Criterion.

*p < .05
4.2 Results of Qualitative Analyses

Table 7 provides descriptive statistics for the 15 participants in the qualitative follow-up study. Participants’ current marriages had a mean duration of 23.3 years ($SD = 12.4$). All women reported that their husbands were non-Hispanic African American. Five participants reported that this relationship was a first marriage for both them and their husband, and one-third of the participants (5) reported having children with their husband. The mean DAS-7 score was 22.3 ($SD = 6.9$), with five women reporting scores below 21, the cutoff often used to indicate marital distress.

In the interviews for this aim, participants described a range of ways that their breast cancer diagnosis had affected them and their marriages. In the results below, participant numbers are unique identifiers generated for the qualitative study. Themes emerged related to the health context of the couple, changes in relationships over time, support provided by husbands, cancer’s effects on husbands’ mental and physical health, support participants gave to their husbands, ways clinicians could support couples, and quality of medical care. Although most participants described successful negotiation of cancer-related issues with their spouses, several reported being in distressed relationships that did not provide them with adequate support.
Table 7 Characteristics of married African American breast cancer survivors participating in the qualitative follow-up study (N = 15).

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD) or % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationship characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>Years married</td>
<td>23.3 (12.4)</td>
</tr>
<tr>
<td>Relationship adjustment (DAS-7)</td>
<td>22.3 (6.9)</td>
</tr>
<tr>
<td>Husband African American</td>
<td>100.0% (15)</td>
</tr>
<tr>
<td>Total times married (self)</td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>60.0% (9)</td>
</tr>
<tr>
<td>Two</td>
<td>33.3% (5)</td>
</tr>
<tr>
<td>Three</td>
<td>6.7% (1)</td>
</tr>
<tr>
<td>Total times married (husband)</td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>46.7% (7)</td>
</tr>
<tr>
<td>Two</td>
<td>40.0% (6)</td>
</tr>
<tr>
<td>Three</td>
<td>13.3% (2)</td>
</tr>
<tr>
<td>Children with partner</td>
<td>33.3% (5)</td>
</tr>
<tr>
<td><strong>Clinical information</strong></td>
<td></td>
</tr>
<tr>
<td>Cancer stage</td>
<td></td>
</tr>
<tr>
<td>Early</td>
<td>53.3% (8)</td>
</tr>
<tr>
<td>Late</td>
<td>46.7% (7)</td>
</tr>
<tr>
<td>Surgery type</td>
<td></td>
</tr>
<tr>
<td>Breast conserving surgery</td>
<td>73.3% (11)</td>
</tr>
<tr>
<td>Mastectomy</td>
<td>26.7% (4)</td>
</tr>
<tr>
<td>Received hormone therapy</td>
<td>93.3% (14)</td>
</tr>
<tr>
<td>Received radiation</td>
<td>80.0% (12)</td>
</tr>
<tr>
<td>Received chemotherapy</td>
<td>46.7% (7)</td>
</tr>
<tr>
<td><strong>Demographic information</strong></td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td></td>
</tr>
<tr>
<td>&lt;$25,000</td>
<td>40.0% (6)</td>
</tr>
<tr>
<td>$25,000 - $49,999</td>
<td>33.3% (5)</td>
</tr>
<tr>
<td>≥ $50,000</td>
<td>26.6% (4)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>&lt;12th grade</td>
<td>20.0% (3)</td>
</tr>
<tr>
<td>12th grade/GED</td>
<td>13.3% (2)</td>
</tr>
<tr>
<td>&gt;12th grade</td>
<td>46.7% (10)</td>
</tr>
<tr>
<td>Age at time of interview</td>
<td>60.2 (7.4)</td>
</tr>
<tr>
<td>Years since enrollment in parent study</td>
<td>4.2 (1.0)</td>
</tr>
<tr>
<td><strong>Psychosocial variables</strong></td>
<td></td>
</tr>
<tr>
<td>Social support (MOS-SS)</td>
<td>86.9 (18.2)</td>
</tr>
<tr>
<td>Religion/spirituality (SBI)</td>
<td>41.6 (6.4)</td>
</tr>
<tr>
<td>Depression (CES-D)</td>
<td>11.1 (12.4)</td>
</tr>
</tbody>
</table>
Note: Social support, depression, spirituality, and income scores come from the final interview for the parent study; for one participant who reported income at the baseline interview only, income at baseline was used. Education was assessed only at baseline. Clinical information was taken from the medical record. Relationship information was obtained at the qualitative interview.

4.2.1 Health Context of the Couple

In addition to talking about breast cancer, participants described the broader health context of the couple. It was clear that, for most couples, breast cancer was not the only health condition they faced. Six participants said they had high blood pressure, and four participants reported being diabetic (two diagnosed pre-breast cancer, one diagnosed during treatment, and one diagnosed post-treatment). Other conditions (mentioned by one participant each) included lupus, hyperthyroidism (diagnosed while undergoing cancer treatment), glaucoma, prior endometrial cancer, and prior colon cancer.

Participants reported that their husbands had a range of health conditions as well. Two participants reported their husbands had diabetes (before the participants’ breast cancer diagnosis), and two participant reported their husbands had had congestive heart failure (one diagnosed before and one after her breast cancer). Other conditions mentioned for spouses included gallbladder problems (two spouses), dementia (one spouse), prostate cancer (one spouse), chronic obstructive pulmonary disease (one spouse), glaucoma (one spouse), and possible other cancer (the participant suspected her husband might have had cancer but was unsure).
Taken together, these results show that the health context of married couples can be complex. Breast cancer patients may be living with serious comorbidities, and their husbands may also have chronic conditions requiring care.

4.2.2 Change in Relationships over Time

One theme involved cancer-related change in relationships over time. Participants were asked to describe their relationships with their husbands before their cancer diagnosis, during treatment, and once treatment had ended. Eight participants believed their relationships stayed strong or got better over time. Several people, when asked to describe their relationship before their diagnosis, indicated they saw continuity between their current relationship and their relationship as it was in the past; in their responses, these people often lapsed into present tense when asked to describe their relationship in the past, suggesting they did not differentiate between the time periods. For example, Participant 2 said, “We have a great relationship. You know, just nothing really seems to change.” Many of these participants stated initially that breast cancer did not affect their relationships with their husbands, but often they elaborated further and said they thought their experience with breast cancer had actually made their relationships stronger. For instance, Participant 6 initially said her relationship with her husband seemed to “stay about the same” but later added, “I was just so grateful and... happy that he was right here with me through all that, that it cemented our relationship even more.” Participant 9 also used images of stability and cohesion to describe the positive change in her relationship: “I often say that I always knew my husband loved me… but [after cancer] I really knew he loved me. I mean, that just solidified everything.” Participant 15 emphasized the continuity of her relationship over time, and she also underlined the role faith played in her partnership:
[Our relationship] didn’t change prior to me receiving treatment nor did it change after, as far as my husband’s always been supportive and we’ve always made decisions together. And I’m not going to say we had the perfect marriage, but we… have a wonderful, beautiful marriage…. And because God is in our lives, make it easier. Our faith has made it this way.

These participants did not believe cancer diagnosis and treatment had caused a disruption in their relationships.

A few participants reported problems with their relationships at some point in the previous several years. Three participants reported having difficulties in their relationships prior to cancer; for two of these participants, their initial problems got better over the course of cancer treatment and survivorship. Participant 7 reported that arguments over sexual compatibility abated when cancer treatment reduced her sex drive and made it more comparable to her husband’s. Participant 14 had suspected her husband of infidelity prior to cancer, but she reported that they had become re-acquainted and their relationship now “is much better than it’s been in a long time.” Participant 12 was unusual in this sample in that she reported she and her partner had had major problems due to using drugs and alcohol. By the time of her cancer diagnosis, she was clean, and her diagnosis caused her husband to cut back on his substance use in order to support her. She reported that her relationship got temporarily better, but post-treatment, “We still haven’t come back together”; she described her relationship as currently “horrible.” Participant 1 reported having had a strained and distant relationship for many years. She observed that her husband’s lack of support disappointed her during her cancer treatment; currently, she said, “We just kind of coexist.”

Three participants reported the quality of their relationships with their spouses had declined, a change they attributed to their diagnosis and treatment. These participants tended to use images of distance or withdrawal to describe the changes in their relationships. Participant 4
reported that after her diagnosis, her husband “was there, but he wasn’t there… Everything was basically put on me. Everything. Household chores, everything…. I think it was the breast cancer that started it… because before that we did have a relationship.” Participant 11 remembered that “we was a happy family” before her diagnosis, but said that after cancer her husband “kind of pulled his self away a little bit.” Participant 8 described a similar emotional withdrawal and noted that her husband “became a little less, I’d say, tender-supportive…. He started pulling back… and so that left me feeling alone…during the whole process. I wanted more hugs and, you know, I wanted to cry on somebody’s shoulder, and he calls that being a wimp.” Participants believed this withdrawal may have been due to their husband’s fears about mortality due to cancer. Two of the participants who reported decline mentioned during the course of their interviews that they had been eager to participate in this study because they were seeking answers about how to make their relationships better again.

Taken together, these varied relationship trajectories show that there is no one single way that married couples respond when one partner is diagnosed with cancer. Although the majority of women reported that their relationships stayed the same or got better during breast cancer treatment and survivorship, some participants reported that at least some aspects of their relationships caused them distress, and three of these participants believed the decline in the quality of their relationships was due to cancer.

4.2.3 Husbands’ Support of Their Wives

Another theme involved social support that participants received from their husbands. Many participants felt supported by their husbands throughout their treatment. The most common kind of support mentioned was emotional support, which was often conceptualized as simply “being there.” Tangible support was the second-most mentioned kind of support, and it
included activities such as cleaning, cooking, and providing transportation to doctor’s appointments.

Many husbands played a crucial role in providing emotional support to their wives. This support was not necessarily verbal and sometimes entailed being a sympathetic presence in women’s lives. The imagery of “being there” stands in contrast to the images of distance and withdrawal used above to describe unhappy relationships. Participant 2, for example, said, “My husband, he support me a lot…. Just being there. ’Cause really, when you go through a situation like that, just knowing you got people by your side, that helps.” Participant 10 echoed those words and also emphasized the role faith played in her relationship:

[My husband] was just there…. I couldn’t ask for a better support system. I didn’t need no one but him and God, because it was no one else necessary. God gave me the strength and the faith. My husband done it all. By him being so faithful, and relied on God for everything, even the strength for him to have to deal with a wife that was so sick.

Several participants made similar comments about their husbands’ faith underlying their supportive behavior. Participant 3 linked the emotional support of “being there” to the tangible support her husband provided:

He’s always helpful, so he … did the same things that he always did. If I need to stay in bed, I can stay in bed. If I needed somebody to go and get something, he would go and get it… He would clean if needed to clean…. So he was just always there at every step, the treatment, the doctor’s appointments, all of that.

In several cases, husbands’ provision of tangible support was interpreted by wives as part of being present emotionally. In some instances, women had to spell out what they wanted from their husbands. Participant 13 noted that her husband initially treated her cancer “like I had a tooth pulled” and was not overly solicitous because she did not have an extended stay in the hospital. When she made her needs clear, however, he helped with housework and let her rest, and she concluded, “[H]e’s been real supportive. But I do have to tell him what to do.”

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Some women were dissatisfied with the level or type of support provided by their husbands. Participant 4 experienced tangible support but not emotional support: “For all my treatments, he was there. It’s just that…I guess his focus got away from it….I guess he may assume maybe I was well. I’m not even sure anymore.” Her response suggests that tangible support from a spouse may not be sufficient by itself to make a woman feel supported; instead, this participant longed to be the “focus” of her husband’s attention. Participant 8 found her husband lacking in both emotional support and tangible support:

[The] things that I couldn’t do because of the cancer, he… tried to do and found out he couldn’t do, so it was like a failure to him. He felt like it was a failure, so he stopped doing them…. I think the diagnosis changed him and me because I think I might’ve pulled back a little bit too…. I felt like he should have known when I needed a hug.

In this case, the participant saw her husband’s lack of tangible support as disappointing, which led her to withdraw emotionally.

4.2.4 Body Image and Sexual Relationships

In many interviews, participants discussed the role that husbands could play around body image and engaging in sexual intercourse. One theme that emerged was ways that husbands could offer their wives reassurance about their attractiveness and help them have a positive body image. In many cases, women reported struggling to accept their bodies after surgery and side effects of cancer treatment. In particular, they reported emotional distress from hair loss and from having their breasts altered by surgery. Several participants described the contrast between their husbands’ unwavering support around issues of body image and their own conflicted response to their bodies. Participant 6 said, “My hair coming out didn’t seem to bother him…. It won’t come back and that’s bothering me, but it didn’t bother him.” Participant 10 reported, “I get sad sometimes… about my body…. He won’t permit me, in his face, to put down myself or
say something negative about my body…. I don’t think my husband looks at me any different. I really don’t. It’s me that looks different at myself.” Several participants described how husbands emphasized that they valued their wives for more than their physical appearance or found them beautiful regardless of changes to their body. Participant 15 described her husband’s emotional support around body image: “He said, ‘You are beautiful.’ He said, ‘I did not marry you for your hair.’ He made me feel beautiful even when I didn’t feel beautiful.” Participant 9 reported that her husband reassured her in similar terms: “He said, ‘You have no idea how much I love you, do you?... I didn’t marry you for your hair or your boobs… You got nice boobs and you got beautiful hair, but that’s not why I married you.’ He said, ‘We’re in this together, we’re good.’” This support around body image provided women with reassurance that they were still valued and attractive and that their husbands’ support was not tied to physical attributes such as breasts or hair.

Participant 3 provided examples of a husband taking an active role in helping his wife adjust to her changing body. She described how her husband helped shave her head when her hair became brittle and took topless pictures of her the night before her mastectomy:

I said to him that I’m going to have surgery tomorrow, and I think I want a picture of both my boobs… So he went and got the camera. And I said, “Now, we need to make this not look obscene…” So I tied my hair back and… I sat in the chair or on the foot of the bed ’cause I think I didn’t want to be near a bed….So we took pictures of my boobs and that was it.

In this case, her husband helped her exert some control over the changes that were happening to her body.

Several women noted that cancer treatment could lead to problems with body image or sexuality that caused difficulties between partners. Participant 12 was not interested in sex and did not feel comfortable letting her husband see her post-treatment body: “My sex drive is not
like it… used to be. And then I’m, you know… [gestures at breasts] one little one, one big one and, you know, dress up when he come, I’m throwing… my wig on and a bunch of clothes and… he don’t get to see what he wanted.” Two participants who were in good relationships themselves reported having observed other couples in which a male partner was unsupportive of a female partner with breast cancer around issues of body image. Participant 10 observed that, for some men, “breast cancer takes them for a ride…. I’ve just seen how men in some instance have women that done went through breast cancer [and] make them feel they’re not pretty as another lady that has her own breasts.” Participant 15 reported seeing similar dynamics in her own family: “A lot of [spouses] are not supportive…. [My sister is] still married, but I think in a negative way…. She never let her husband see her bald…. I don’t think her husband even saw anything up here [gesturing at her chest]…. And it’s been three years.”

Another important theme that emerged involved negotiating issues related to sexual relationships. Although the interview questions did not specifically address sexual issues, eight participants raised the topic themselves. Most of them reported lower sex drive or other treatment side effects (e.g., pain) that interfered with intercourse. Women in strong relationships described two main ways of negotiating these difficulties. The first was to engage in sexual activities besides intercourse. Participant 2 noted, “I don’t really want it [sex], and sometime if I do, it’s kind of pains for us… but it’s all right…. You don’t really just have to have sex if you do other things. So it’s good.” Participant 10, who talked extensively about the importance of sexuality, said, “It’s other ways of being passionate, which we found out, you know, years and years ago. It’s other ways to have sex without having sex…. You know, dirty talk…. It’s a lot of ways to stimulate a woman.” “Doing other things” allowed women to stay connected to their partners without engaging in activities they found aversive or painful. The second successful
strategy used by couples was postponing intercourse until the participant was ready to resume sexual activity. Participant 14 noted that when she was going through treatment, “I just didn’t want to be touched…. We’re back to normal now. He was kind of—wasn’t frustrated, but just touchy feely, and I said, ‘No.’ I said, ‘Uh-uh, we gonna have to wait on this.’” Both of these strategies rely on patience, communication, and understanding.

Women in unhappy relationships described the change in their sex lives as causing permanent fractures in the relationship. Participant 4 described how her hot flashes led to a change in sleeping arrangements:

I moved out of the bedroom ’cause he didn’t want to give me the bedroom. I moved into the basement where it was much cooler. So that really put us at not close at all. Where we just basically became friends. And you know what I mean by friends, right? ... Nothing going on with friends.

Participant 12 noted that now that her treatment was over, “I don’t have the drive… That’s what keep a man…. You can have problems in the relationship, but then you all can make up. Now, it’s like…. No hug. No kiss. No make-up.” These women saw the lack of a sexual relationship distressing in part because it indicated a lack of emotional closeness.

### 4.2.5 Attributions About Behavior

Several participants’ responses showed that it was not only a spouse’s actions but the attributions a participant made about those actions that affected whether a woman felt supported. For example, Participant 1 and Participant 6 both described husbands who did not cook for them. According to Participant 1, “I can remember not eating…because [my husband] didn’t fix me anything to eat…. I think that just kind of…showed me his true colors ’cause I think I would have been different had he been going through something like that.” She interpreted his lack of cooking as revealing the “true colors” of his character. Participant 6 found her similar situation
more humorous: “His cooking is, you know, terrible. And he can’t even make a good breakfast like oatmeal… but that’s alright. You know, we manage. I couldn’t eat anyway.” She saw her husband’s lack of cooking skills as a part of who he was but did not believe that characteristic revealed anything troubling about their relationship or about him as a person.

The same held true for husbands’ reactions to physical side effects. Again, Participant 1 made negative attributions about her husband’s reaction to her surgery: “If he sees an incision… he goes, “Oh, God!”… I just took it as, you know, This is grotesque.” Participant 5 described similar behavior in a more sympathetic way: “He couldn’t stand to look at [the incision site]…. I could change [the bandage] myself, but he said he couldn’t stand to look at that. [Laughs.] … It was gross-looking, too!” In this case, the participant sympathized with her husband’s perspective and did not treat his reaction as a global judgment about her attractiveness. Both pairs of examples show that similar behavior could be interpreted very differently in the context of different relationships. This suggests that perceptions of support are derived both from husbands’ behaviors and their wives’ interpretations of those behaviors.

### 4.2.6 Cancer’s Effects on Spouses’ Mental and Physical Health

One theme involved the effect of breast cancer on spouses’ mental and physical health. For the most part, participants did not believe cancer had affected husbands’ physical health. Participants expressed more mixed views about the influence of their breast cancer on their husbands’ mental or emotional health.

The majority of participants reported that they did not think that their cancer had affected their spouses’ physical health; those who did saw a link between emotional and physical health. Participant 12 believed her husband’s emotional and physical health were affected due to the fact that he cut back on his substance use while she was going through treatment: “He changed…. 
He got mean…. He got agitated…. [He] was trying to be there with me… and I guess like trying to wean himself off [drugs and alcohol]. Couldn’t get as much as he want, ’cause he was there with me.” Two participants expressed uncertainty about any physical effects their cancer may have had on their husbands, but both saw emotional health and physical health as intertwined.

Participant 15 said,

It’s hard to say [how cancer affected his health], because I know congestive heart failure, I don’t think it’s stress-related, it’s other internal things. But stress may have been a contributor…. I say if it did, it was a very, very, very tiny bit…. I think he might have been emotionally revved up…. It did affect him emotionally.

Participant 6 saw a similar link between emotional and physical health, and she too believed her husband was more affected emotionally than physically:

I’m sure [the cancer diagnosis] worried him. And I’m one of the people that believes that severe worry and stress can affect you physically…. I don’t think that my cancer diagnosis directly affected him physically. I think it was more mental or psychological…. He doesn’t share anything with me. What man does? [Laughter.]

Her comment about gender was echoed by other participants who believed that men do not share their feelings as much as women do, which led to uncertainty about the possible effects cancer may have had on husbands.

Participants expressed a great deal of uncertainty about whether cancer may have affected husbands’ mental or emotional health. Five participants stated outright that they did not believe cancer had had an effect on their husbands’ mental or emotional health. Others were unsure, in most cases because husbands did not discuss the topic. Participant 4 said, “I don’t know how the breast cancer affected him. I’m not sure because he didn’t talk about it. He said it didn’t bother him, but I’m not sure.” Several participants believed their husbands had been affected and framed their husbands’ lack of discussion of the topic as protective or considerate. Participant 10 said, “My husband probably dealt with something, he just ain’t never tell you. He didn’t tell
me…. I’m quite sure he got frustrated. He got tired. He just never showed it.” Participant 9 said, “He’s like, ‘Oh, I’m good. One of us has got to be the strong one. I know you’re going to worry even though you say you’re not worrying. I know you’re thinking about it. I got you. This is us.’ … So I had to kind of let it go…. I trust that he was fine.”

4.2.7 Support Participants Gave to Spouses

In addition to receiving support from their husbands, participants described ways that they gave their husbands support, either while going through treatment or afterward. Some women influenced their husbands’ health behavior through actions such as making sure their husbands took their medicine, cooking for them, and making doctor’s appointments for them. Several participants reported they helped care for their husbands who had chronic conditions including Alzheimer’s disease, Parkinson’s disease, diabetes, and prostate cancer. Participant 10, whose husband has diabetes, said, “My department is his diet…. I make sure he have three meals a day, and like he get a snack… at the end of the night.” Participant 13, whose husband developed dementia due to Alzheimer’s disease after her breast cancer treatment was completed, said:

I’m more of a support for him than he is for me…. At first, I was fine…. I thought I could handle it. But now I felt like it’s a bit much, and I don’t want to wear myself down taking care of him, and worrying about him, and not taking care of myself, and that’s what I feel like I have done, because it’s like he comes first…. I don’t think he has the ability or the capacity to worry about me.

This participant was grateful for the support her husband had given her during breast cancer but now saw herself as the main provider of support in the relationship.

Another theme described by several participants involved being in mutually supportive relationships. Participant 15 saw this mutual support as rooted in a shared faith: “If he had needed someone to talk to…. He would talk to me first….Our faith is so strong that we just saw
that [breast cancer] was an obstacle… that we were going to overcome…. We found strength in each other.” Participant 7, whose husband was diagnosed with prostate cancer shortly after her breast cancer diagnosis, described taking notes at his doctor’s appointments and doing research for him on the Internet; she concluded, “He supported me and I supported him. And I think ’cause we was there with each other… it brought us closer.” Participant 8 was one of several participants who described how retirement had changed their relationships. She said, “The only one that he has really is me, and especially since we retired…. He relies on me, and I rely on him.” In these examples, women reported that both spouses provided support to each other.

There were also several examples of participants who described not engaging in mutually supportive behavior with their partners. Some participants were unable to engage in such mutual support, especially when going through treatment. Participant 12 said she was unable to provide support to her husband when she was going through treatment: “I was too weak… I laid around a lot. I was sick a lot.” A few participants who reported being in unhappy relationships described themselves as supporting their husbands without receiving support even when going through cancer treatment. Participant 4 said her husband “depended basically on me to still do everything” when she was undergoing treatment. Participant 8 observed that she and her husband both drew on their own inner resources but were unable to connect with one another: “The cancer leads us to get stronger, but stronger individually.” These examples show that not all women were in relationships in which both partners were able to support one another.

Another theme involved husbands not seeming to need or want support from their wives or others. This theme related to the beliefs described above that cancer did not affect husbands’ emotional or mental health. Participant 10 stated that it was important to her husband that he was the one providing support to her: “[He] didn’t want no support. I was his wife, and he
of him. Everything.” Several participants shared this belief that their husbands did not seem to need or want support from them. Two participants elaborated that even though their husbands did not seem to want support, they attempted to provide it to their husbands anyway. Participant 7 gave her husband emotional reassurance even though he did not ask for it: “[It] wasn’t something he acted like he wanted or needed. But I believe that they need things just like we do, so I would tell him… ‘It’s okay. We gonna make through,’ you know, verbally, but it wasn’t like he acted like he needed it and I would just do it because I believed it.” Participant 3 also believed that her husband needed support when she was dealing with cancer even though he did not ask for it, and she arranged for him to get it from people other than her:

I don’t know if he needed support from me or if he even felt that he needed support, but I felt that he needed support because I know him very well, and I know that if something is not right with me, it affects him, even though he doesn’t show it…. So I called the people that I knew could support him, his brothers and his sisters.

Both women considered it their job to make sure their husbands had support, even if their husbands did not ask for it. Participant 3’s response suggests that other family members can play an important role when one partner is temporarily unable to support the other due to events such as illness.

4.2.8 Ways to Help Couples

Another theme involved how doctors and other clinicians could help couples face cancer together. Most participants mentioned that allowing or inviting a spouse to come to medical appointments is helpful because it allows spouses to hear information from the doctor or clinician first-hand. Participants said that doctors could provide spouses with information about treatment, side effects, or the emotional impact of cancer on women or couples. Speaking as a
woman who felt her husband was unsupportive, Participant 4 said, “Preparing that husband would be a great thing…. They need to be sitting right there listening to everything. Understanding what their spouse is going to go through.” Participant 15 echoed the importance of helping spouses see the situation from the patient’s perspective when she suggested that doctors could tell patients and their partners about “emotional downfalls” of cancer treatment because “a lot of people may not be prepared emotionally.” She added that doctors could tell spouses that “the person’s still the same… and she may not feel 100 percent…. Not that they’re marriage counselors or anything, but that was not shared [with us].”

A few participants mentioned written materials or support groups aimed at husbands. For example, Participant 6 said,

Let the couple know that there are resources that they can tap into. And if they are people that are quiet and reticent and don’t really…talk to each other or … are afraid and don’t know how to access resources available to them, it would be very helpful. Even if you don’t talk to a person face to face… if you would give them a packet of information, it would be really, really good.

Overall, women endorsed the idea that doctors could play an important role in helping couples adapt to cancer as a unit.

4.2.9 Quality of Care

In the course of interviews, many participants mentioned contextual factors that affected their health. One theme that emerged from the interviews involved quality of care from doctors and/or the National Cancer Institute-designated Comprehensive Cancer Center where the women were treated. Although the information was not elicited by the interview questions, seven women discussed the quality of their medical care or their relationships with their doctors. Four women went out of their way to praise their doctors and the care they received at the cancer center. Participant 2, for example, said, “I think that [the cancer center] is so great. They are
nice. Everybody was kind to you…. I had a great team.” Participant 6 said that she always felt well-treated even though she was poor, and appreciated the fact that she was able to enroll in multiple research studies. She said, “My surgeon, my oncologist, my radiologist, my primary care physician—I will never leave them…. I will always have the same doctors if I can.” Participant 9 also believed she received excellent care: “I was so grateful for the people that I dealt with [at the hospital]…. Everybody was great…. They were attentive, you know, that made a big difference.” Participant 15 found support not only from medical personnel but also from researchers. Addressing the interviewer, she said, “The support system here [at the cancer center] was top notch…. I mean, even you guys, all of you guys who… work for this particular cause, whether it’s survey, nurses… whatever role you played, I could not say anything negative…. Every experience I had here was very positive.” These responses show the range of support that was available to patients at this National Cancer Institute-designated Comprehensive Cancer Center, including support provided by interacting with research personnel.

Three women expressed concerns about their care or about the communication they received from doctors. Two patients believed that doctors in general were not good at communicating. Participant 3, who reported that the doctors she saw prior to her diagnosis dismissed her symptoms for years, said, “The main thing that I think doctors don’t do—and this is a pet peeve of mine—they don’t listen.” Participant 7 believed, based on her and her husband’s experiences, that doctors do not do an adequate job preparing people for the aftereffects of surgery: “I do understand doctors are busy, and… I think they might take for granted that people know things they don’t know…. Doctors don’t tell you anything…. They tell you the medical part of it, but they don’t tell you the survival part… You don’t really learn it from the doctor. You learn it from other people.” Participant 12, who reported liking her doctor,
still described a lack of understanding about her treatment: “I didn’t see [what the doctor was doing], I didn’t even understand. I didn’t even know what chemo was, radiation was. None of that…. I just did what I was supposed to do. Sat there and took my chemo, laid there and took my radiation. Prayed and just went through.” These responses show that some women did not feel completely supported by their doctors.

Taken together, these interviews provide in-depth information about the social context of breast cancer among African American women and their husbands. Most participants reported feeling supported in their relationships, but some women reported problems, some of which they attributed directly to breast cancer.
Chapter 5: Discussion

This study used multiple methods to extend current knowledge about intimate partnerships and social support in African American breast cancer survivors. Taken together, the quantitative and qualitative results paint a picture of variability and show that responses to breast cancer differ between women and between couples.

Partial support was found for the hypotheses tested in the quantitative analyses. Hypothesis 1, that social support would decline over time, was not supported. Growth curve models showed that although mean perceived social support scores remained stable over time, there was significant variability in social support trajectories among participants. That is, although average support remained stable in the group, some women’s perceived social support scores increased over time, some women’s scores decreased, and some women’s scores remained roughly the same. Hypothesis 2—that psychosocial variables, demographic variables, health variables, and cancer-related variables would predict stable levels (intercept) of social support and systematic change in social support (slope) in individuals—was partially supported. Although none of the variables in the models predicted individuals’ change in social support over time, religiosity, depressive symptoms, and marital status were associated with the estimated initial levels of social support. Higher scores on the measure of religiosity and being married were associated with higher levels of perceived social support, and greater depressive symptoms were associated with lower support. Finally, there was partial support for Hypothesis 3, which stated that change in social support over the first year following diagnosis would predict depressive symptoms, general health, and surveillance mammography at two years. A decrease in social support during the first year after breast cancer diagnosis was associated with negative consequences including increased depressive symptoms and decreased self-reported general
health at two years. Exhibiting a change in social support was not, however, associated with receipt of surveillance mammography.

In the quantitative study, high mean social support scores at baseline (MOS-SS mean = 81.9, SD = 19.8) indicated that most participants perceived themselves to have high levels of social support. This baseline social support mean score was higher than the mean of 70.1 reported by the developers of the MOS-SS (Sherbourne & Stewart, 1991) and slightly lower than the mean of 84.6 found in a sample of white and African American breast cancer survivors from the same metropolitan area (Thompson et al., 2013).

The stability of social support over time was unexpected given past research (Den Oudsten et al., 2010; Courtens et al., 1996; Bloom & Kessler, 1994; Levy et al., 1992), especially because a previous study of early-stage breast cancer patients found that African American patients treated at this same cancer center experienced steeper decline in social support over time compared to White women (Thompson et al., 2013). Because the prior study at this cancer center included only early-stage patients and used slightly different intervals between time points than the current study, post hoc growth curve analyses were conducted excluding late-stage patients and omitting measurements from baseline in order to make the timing of measurements roughly comparable. Those analyses also did not find any statistically significant change in mean social support over time. A comparison of income distribution between the current sample and African American participants in the previous study (Thompson et al., 2013) found that the distribution was largely similar, so the differences in findings were most likely not driven by income. It is possible that this difference in social support change between studies could be explained by factors such as new forms of support available at the cancer center or in the broader community. Several of the participants from the qualitative study believed they had received
excellent care at the cancer center and spoke of receiving support from their doctors, from other staff, and from research personnel. It is possible that these interactions helped mitigate the effects of a cancer diagnosis on participants’ perceived social support.

Results from the growth curve models underlined the importance of both depressive symptoms and marital status to stable levels of social support. Being married was associated with a higher stable levels of social support, which is consistent with previous research indicating that intimate partnerships such as marriage can be an important source of support for African American women with cancer (Von Ah, et al., 2012; Ashing-Giwa & Ganz, 1997). Also consistent with prior work, depressive symptoms at baseline were associated with levels of social support (Patten et al., 2010; Thompson et al., 2013). There was significant variability in social support trajectories over time among the women in this sample, but none of the variables included in the models predicted this change.

Results indicated that both stable and changing aspects of social support had an effect on quality of life outcomes two years after baseline. The finding that a greater decline in social support was associated with lower general health and greater depressive symptoms two years after a cancer diagnosis was consistent with previous research (Thompson et al., 2013; Patten et al., 2010) and indicates that declines in perceived social support are problematic in African American breast cancer patients. Receipt of surveillance mammography at two years was not, however, predicted by social support slope or intercept. This may be due to the fact that only a relatively small percentage of women in this sample (13.5%) who were eligible for screening mammography did not receive surveillance mammograms.

Both the quantitative and qualitative analyses point to the importance of religion in quality of life and adaptation to cancer in this sample of African American breast cancer patients.
In the general population, religious beliefs and practices are associated both with stronger intimate partnerships and higher levels of social support (Koenig & Larson, 2001). Researchers also have found that in African American women religion can play an important role in coping with breast cancer (Ashing-Giwa et al., 2004). In the quantitative analyses, SBI score was significantly associated with social support intercept. In the qualitative study, several women saw religious beliefs as underlying their husbands’ supportive behavior or saw religion as influencing their interactions as a couple. This result is consistent with findings from quantitative dyadic cancer research that has found spillover effects between one partner’s spiritual well-being and another partner’s quality of life (Kim, Carver, Spillers, Crammer, & Zhou, 2011).

Results of the qualitative interviews of married women with breast cancer provided an in-depth look at how their diagnosis of cancer affected not only themselves but also their husbands and their relationships. As in the quantitative results, there was variability in responses. Based on participants’ interviews, more than half of the couples navigated the challenge of a breast cancer diagnosis successfully. Many women saw their husbands as playing a key role in providing support and reported that they provided support to their husbands as well. A few of women, however, reported that their relationships caused them considerable distress, and several women attributed a decline in the quality of their relationships to breast cancer.

Participants described partners as giving them emotional support, providing tangible assistance, and helping them adjust to their post-treatment bodies and sexuality. These findings are consistent with prior work showing that cancer can lead to concerns about sexuality (Baker et al., 2005), and that issues surrounding sexual relationships and body image can affect intimate partnerships in the context of cancer (Ashing-Giwa et al., 2004). Many women described feeling
supported by their husbands, and some of them described this support as taking the form of “being there.” This description is consistent with the idea that perceptions of support from an intimate partner may be based in part on noncognitive processes, including the recognition that a sympathetic person is nearby (Uchino et al., 2012). The fact that many women saw their husbands’ support during breast cancer treatment as a continuation of the husbands’ usual supportive behavior is consistent with the idea that “everyday support” enacted during times when a couple is not facing a major stressor can lay the groundwork for support during times of stress (Lakey & Orehek, 2011; Thoits, 2011). It is also consistent with women’s reports of providing support to their husbands.

In some cases, it was not only husbands’ actions but the participants’ attributions about those actions that influenced perceptions of support. This finding is consistent with models of couple interaction such as the Relationship Enhancement Model (Cutrona, Russell, & Gardner, 2005) that depict perceptions of support as stemming from both a partner’s actions and attributions about those actions. Participants’ responses also emphasize the importance of relationship quality as opposed to the simple presence or absence of a relationship (Robles et al., 2014). Women who were in distressed marriages did not see themselves as obtaining adequate support from those relationships.

Participants’ interview responses also show the importance of looking beyond a single condition such as breast cancer to take into account the larger health context of the dyad. In this sample, there was considerable comorbidity for patients and co-occurrence of chronic conditions for partners, and several participants reported providing support to husbands faced with chronic conditions such as diabetes or dementia. In a sample with a mean age of 60, it is perhaps unsurprising that many patients and their husbands faced multiple chronic conditions, but it is an
important contextual factor to keep in mind when considering treatment options, caregiving responsibilities, and delivery of psychosocial interventions. If researchers or medical professionals consider only one disease at a time, they may miss the broader health landscape of the couple and not be aware of multiple demands on a couple’s energy, attention, and finances.

It is intriguing that most women did not think their cancer diagnosis affected their husbands’ physical or mental health. Recent dyadic data analyses have found small but significant effects of a cancer diagnosis on the physical and mental health of spouses of cancer patients (Litzelman et al., 2016; Valle et al., 2013). Given that many couples faced multiple health issues, it is possible that small effects of one partner’s particular chronic condition on the other may be difficult to detect at the level of individual couples. Women’s uncertainty about the effects of their breast cancer on their husbands’ mental/emotional health was also striking, because it indicated that many couples—even those with strong relationships—did not have discussions about the husbands’ emotional reactions to their wives’ cancer. Sometimes women saw this lack of discussion as protective, and sometimes they viewed it as an attribute of men in general or of their husbands in particular.

Results from the qualitative study are consistent with the idea that a breast cancer diagnosis is not a crisis for every woman or every couple (Hagedoorn et al., 2008). Indeed, most women in the qualitative study believed their relationships stayed the same or became stronger during treatment and into survivorship. A smaller number of women in the qualitative study, however, reported significant distress from their relationships; five participants had DAS-7 scores indicating marital distress, and three participants believed their relationships became much worse as a result of their cancer. These findings are especially interesting given concerns about selection bias in studies of relationships. One dyadic study from the Netherlands on
adaptation to illness suggested that patients and partners who choose to enroll in such studies may be less distressed and in better-functioning relationships than those who choose not to enroll (Hagedoorn et al., 2015). In another dyadic study of predominantly white breast cancer patients, participants were more likely to have higher quality of life, greater partner support, and higher income and were more likely to be white than those who chose not to participate (Christie, Meyerowitz, Stanton, Rowland, & Ganz, 2013). Even though the current qualitative study was not dyadic, it is possible that the women who chose to participate in a study on relationships may have had stronger relationships than women who chose not to enroll. If that were the case, African American women in married relationships in the general population might experience higher levels of distress than participants in the current study, which highlights the need to assess relationship distress in breast cancer patients and offer resources to help patients cope.

It is also possible that findings for predominantly white samples about the effects of cancer on relationships do not hold in African American populations. Von Ah et al. (2012) found reports of relationship distress among African American cancer survivors that were much higher than results from predominantly white samples. Two participants in the current study specifically said that they had volunteered to participate in the study because their relationships were causing them distress.

5.1 Strengths and Limitations

The current study has both strengths and limitations. Strengths include the use of a mixed methods approach and collection of information from multiple sources, including self-reported questionnaires, in-depth interviews, and medical records. In the present study, the quantitative analyses of longitudinal data from and about African American breast cancer survivors employed sophisticated modeling techniques, and there was a high rate of retention
over two years. The qualitative analyses allowed for an in-depth exploration of how breast cancer affects married African American women and their partners and were intended to lay the groundwork for future dyadic studies in this population. An important innovation of this study is the exploration of African American women’s perceptions of how their cancer diagnosis affected the physical health of their spouses, and the conceptualization of cancer patients as both givers and recipients of support.

This study also has several limitations. As is often the case with secondary data analyses, the Survivor Stories dataset did not contain some of the variables that might be of interest in examining the current research questions. For example, some potential factors that might influence participants’ perceptions of social support (e.g., history of abuse or trauma, or early family context; see Umberson, Crosnoe, & Reczek, 2010, and Uchino, 2009) were not assessed. It would also have been helpful to have a measure of relationship satisfaction and relationship-specific social support in the larger Survivor Stories Study. Another limitation of both the quantitative and qualitative components was a lack of self-reported data from participants’ partners. For the qualitative study, women reported their perceptions of how cancer had affected their husbands, but their husbands’ self-report may have provided different or complementary information. The retrospective nature of the qualitative study also means that recall bias may have been an issue (Szklo & Nietro, 2007); participants’ current views of their relationships may have colored their perspective on past events (Gottman & Silver, 1999). Future prospective research that includes both members of a couple would help to address these issues.

The original Survivor Stories study was designed to test the effects of a video intervention on breast cancer patients’ quality of life. The current intent-to-treat analyses controlled for study arm but did not include information about other intervention-related
variables such as dose (i.e., the amount of time participants spent using the intervention). Future analyses examining the effects of the intervention may benefit from taking such variables into account.

There are limitations to the social support measure as well. The Medical Outcomes Study Social Support Survey is a global measure of perceived support and does not provide information about the source of this support. It also does not provide information about negative social interactions or intrusive support attempts, factors which may be important to consider when evaluating the balance between the positive and negative consequences of social ties (Umberson & Montez, 2010). Strategies such as community based participatory research could be valuable both in assessing existing social support measures for use in low-income or African American populations and in developing new measures of social support that capture additional dimensions of support. In addition, more needs to be known about the clinical significance of MOS-SS scores and the changes in those scores. These analyses showed that declines in social support over the first year after a breast cancer diagnosis were associated with higher levels of depressive symptoms and lower self-reported general health at two years after diagnosis, but if such information is to inform clinical practice it will be important to determine what levels of decline in social support are clinically meaningful.

Although several women mentioned faith in the qualitative component of the study, the measurement of religion (SBI) used by the parent study limited exploration of this construct. The SBI is designed in part to measure social support derived from a religious community. The SBI social support subscale showed only moderate correlation with the MOS-SS, however, and by itself the subscale was unrelated to social support slope and intercept. Future research investigating religiosity and spirituality among cancer patients should consider how these
constructs may differ from social support. Doing so may entail using multiple measures of religiosity, or deliberately selecting measures (e.g., the Duke Religion Index; Koenig, Perkerson, & Meador, 1997) that measure religiosity without intending to measure social support. Such research can help tease out specific pathways by which religious beliefs and practices may affect physical and psychosocial health (Howsepián & Merluzzi, 2009; Thuné-Boyle, Stygall, Keshtgar, & Newman, 2006; Stefanek, McDonald, & Hess, 2005), separate from the effects of perceived social support.

Finally, results from this study may not generalize to other populations. The African American women in this study came primarily from one urban area, and the sample was predominantly low-income. The vast majority of participants in the quantitative study, and all the participants in the qualitative study, received treatment at a National Cancer Institute-designated Comprehensive Cancer Center. This care may be very different from what patients receive in other treatment settings. Several women in the qualitative study shared that they believed they had received excellent care from doctors and medical staff, and two women mentioned participating in multiple research studies, which indicates that women treated at this cancer center may have had many high-quality resources available to them for treatment and support. In addition, the average ages of participants in the quantitative and qualitative studies (56.0 and 60.0, respectively) suggest that most participants in both studies were post-menopausal; results may differ in samples of younger women.

5.2 Implications for Research and Practice

Findings from the qualitative and quantitative studies suggest several possible directions for intervention. Medical professionals should consider screening patients for depressive symptoms, social support, and relationship distress in order to provide referrals to empirically
supported treatment as needed for either individual mental health problems or relationship issues. The association between depression and social support is especially important given that there are empirically supported treatments for depression (Cuijpers, van Straten, Andersson, & van Oppen, 2008). Screening for psychosocial factors is also consistent with the Institute of Medicine’s recommendation for survivorship care plans for cancer patients (IOM, 2006). Results from the qualitative study suggest that survivors may benefit from survivorship care plans that take into account the social context of the patient, including mental health needs, supports from organized religion, and support from intimate partners. In addition, medical professionals could use such assessments to help patients find alternate forms of support (e.g., support groups) if they lack support in their daily lives.

Second, the present qualitative findings, if replicated in future research, may help inform interventions for couples. There has been increasing interest in interventions that are either dyadic or that target caregivers/partners of patients facing chronic disease (Northouse et al., 2012; Regan et al., 2012; Northouse et al., 2010, Martire et al., 2012). In the qualitative interviews, women expressed openness to receiving advice or referrals from their doctors about addressing relationship issues. The fact that attributions about partner behavior were related to relationship quality in this study suggests that individual-based or couples-based therapy that examines cognitions as well as behaviors (i.e., cognitive behavioral therapy) might help couples establish or re-establish trust and intimacy. In addition, other types of interventions such as culturally tailored print materials (Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2003) or culturally appropriate support interventions that include intimate partners of cancer patients (e.g., Campbell et al., 2007) could be leveraged to support partners or to help partners support patients going through treatment. Public health practitioners may also consider
interventions at the neighborhood or community level in order to build community engagement in low-income areas and increase support available both to people in the general population as well as to those who are living with diseases such as cancer (Gehlert, Small, & Bollinger, 2011; Holmes et al., 2008). Providing communities with resources such as “neighborhood support coordinators” may not only help breast cancer patients receive individualized support and but also allow residents to engage with their communities, connect with resources, and solve broader health-related and social issues (Gehlert et al., 2011).

The idea that “everyday support” may lay the groundwork for support during times of stress suggests that interventions to promote healthy relationships in general may help people feel supported later when a health condition occurs. Although interventions promoting healthy relationships in the general population or among low-income couples have had disappointing results (Johnson, 2012), broader policy interventions promoting education, delayed childbearing, and economic development earlier in the lifespan may hold promise in increasing family stability and relationship quality (Cherlin, 2014; Sawhill, 2014). If relationships are stronger in their early stages, this may, in turn, affect the support available to people when a health condition develops.

In addition to the suggestions for future research mentioned in the limitations section, the findings from this study raise further questions. Research is needed to explore additional factors that affect social support and relationships in African American women with breast cancer. Based on prior research (Thompson et al., 2013), for example, it is striking that none of the variables investigated in the current study predicted individuals’ change in social support over time. This suggests that future work designed to study social support specifically should investigate additional contextual predictors of social support in this population. Such research could investigate factors suggested by the literature to affect quality of life in cancer patients,
including relationship quality (Robles et al., 2015) or neighborhood characteristics (Gomez et al., 2015). The present study helps add to the literature about African American women with breast cancer, but more needs to be known about factors associated with quality of life in survivorship among other racial and ethnic groups as well.

In light of recent changes in family forms in the U.S., researchers should also investigate the support women gain from a variety of kinds of intimate partnerships and other relationships. In this qualitative study, most survivors reported that their husbands played an important role in providing support, but only 28% of women in the Survivor Stories Study were married at the time of diagnosis. Given current shifts in family patterns in the U.S., especially among African Americans (Kreider & Ellis, 2011; Goodwin et al., 2010; Banks & Gatlin, 2005), additional research is needed about other relationships, including dating relationships, cohabitation, and same-sex couples. The number of people reporting cohabitation in the Survivor Stories Study at baseline was small (3, or 1.3%), but as current cohorts of women age it is likely that cohabitation will emerge as a prominent form of intimate partnership among cancer survivors as well the general population. Women were recruited into Survivor Stories before same-sex marriage was legalized in either Missouri or in the United States, and thus all married relationships in this study were assumed to be heterosexual. Given the 2013 U.S. Supreme Court ruling legalizing same-sex marriage nationwide, future research should examine how same-sex married couples support each other both in daily life and as they face chronic disease. In addition, it is also important to investigate the support available to women not currently in romantic relationships or intimate partnerships from sources such as family members (e.g. adult children) and close friends.
5.3 Conclusion

This study provides important information about how breast cancer affects social support and relationships among African American women and their partners, and the findings suggest future directions for research and intervention. Many women in the quantitative study demonstrated high levels of perceived social support, and many in the qualitative study felt supported by their partners. Some women, however, were distressed by their relationships and thought cancer had caused a decline in relationship quality.

As the number of breast cancer survivors in the U.S. continues to grow, it will become increasingly important to address disparities in outcomes between women of different races and ethnicities. One way to do that is to develop culturally appropriate interventions to improve the survivorship experience for patients and their partners. Doing so will require additional research on contextual factors to assure that interventions reflect the unique context and means of support available to patients from different backgrounds. Strengthening social support and intimate partnerships for diverse individuals and couples facing cancer is one way to help reach the Healthy People 2020 goal of creating social environments that promote good health for everyone (U.S. Department of Health and Human Services, 2014).
References


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114


doi:10.1177/0146621677001000306


Appendix A: Interview Guide for Qualitative Study

Thank you for agreeing to participate in this study about how breast cancer affects personal relationships. There are two main parts to the interview: a series of questions you can answer briefly, and then a set of more open-ended questions. Do you have any questions for me before we begin?

Close-ended questions

In this first part of the interview, we would like to find out more about your relationship with your spouse. I am going to ask you a few short questions about your spouse and your relationship.

1. How long have you and your spouse been married? ______ (years)
2. Is this your first marriage? Y/N If no, How many total times have you been married? ______
3. Is this your spouse’s first marriage? Y/N If no, How many total times has your spouse been married? ______
4. How does your spouse describe his/her race?
   _____ American Indian or Alaska Native   _____ Asian
   _____ Black/African American   _____ Native Hawaiian or Other Pacific Islander
   _____ White   _____ Other ______________________
5. Is your spouse Hispanic or Latino?
   _____ Hispanic or Latino   _____ Not Hispanic or Latino
6. Do you and your spouse have children together? Y/N If yes, How many? ______
7. Do you have children who are living at home? Y/N If yes, How many? ______

Next, I am going to ask you seven questions about your relationship with your spouse as it is right now. I will show you a chart that goes with each response.
The Dyadic Adjustment Scale-7 (Hunsley, Best, Lefebvre, & Vito, 2001) was administered at this point in the interview.

Open-ended questions

In this next part of the interview, I would like to ask you about your relationship with your spouse before, during, and after your breast cancer diagnosis and treatment. For these questions, feel free to take your time in remembering what happened. Please answer in as much detail as you would like.

1. First, I’d like you to think back to the time before you were diagnosed with breast cancer. Please tell me about your relationship with your spouse before your diagnosis of breast cancer. [Probes: How long were you together before your breast cancer diagnosis? What was good about your relationship? Were there negative things about it? Were you both in good health? What activities did you like to do together?]

2. Now, I’d like you to think back about the time when you were diagnosed with breast cancer and when you were going through treatment. Do you think your relationship changed as a result of your breast cancer? [Probes: In what ways did your relationship change?]

3. At the time of diagnosis and during your treatment, were there ways your spouse gave you support or helped you out? [Probe: What kinds of things did he/she do for you? Did your spouse give you emotional support? Hands-on support?]

4. Did you wish you could have gotten additional support or help from your spouse during that time? [Probe: What kind of support would you have liked?]

5. Was there anyone besides your spouse who gave you support or helped you out during that time? [Probe: What did he/she do? Did you have support from other family members? From neighbors? From a church or other community group? From a cancer support group?]

6. During this time, did you find support through media resources such as magazines, videos of breast cancer survivors, or online communities, such as Facebook, chat rooms, or blogs? [Probe: What kinds of resources did you use? How were they helpful or not helpful?]

7. When you were diagnosed with breast cancer and during treatment, were there times when your spouse needed or wanted support from you? [Probe: What kind of support did your spouse need/want? Were you able to give it?]

8. Do you think there were times during this period when your spouse wished he/she could have more support or help? Did your spouse get support from other people? [Probe: Describe those times. Where did he/she get support? What did people do to support him/her?]
9. I’d like you to think for a moment about your spouse’s health during that time. Do you think your cancer diagnosis and treatment affected your spouse’s physical health? [Probe: In what ways was his/her health affected?]

10. During the same time period, do you think your cancer diagnosis and treatment affected your spouse’s emotional health or well-being? [Probe: How?]

11. Try to remember what else was going on in your life during that time. Were there any other health conditions or life circumstances besides cancer that may have affected your relationship with your spouse? [Probe: How did _____ affect your relationship?]

12. Now I’d like you to think about how your relationship with your husband has been since your treatment ended. Did your relationship change once your treatment ended? How would you describe your relationship as it is now?

13. In your relationship today, are there ways you try to encourage each other to be healthy? [Probe: For example, do you influence each other’s eating or exercise? Is that something you’ve always done, or is it more recent? Do you exercise or engage in other healthy activities together?]

14. I’d like you to think back over all the experiences we’ve just been talking about. If you were giving advice to a woman who had recently been diagnosed with breast cancer, what would you want her to know about how cancer affects personal relationships?

15. Based on your experience, how do you think doctors and other health professionals can help couples face cancer together?
## Appendix B: Codebook for Qualitative Study

### [Relationship change over time]

<table>
<thead>
<tr>
<th>Before</th>
<th>Relationship status before diagnosis/treatment of breast cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change.cancer</td>
<td>Relationship changed during diagnosis/treatment (yes or no)</td>
</tr>
<tr>
<td>Change.end</td>
<td>Relationship changed after treatment was over (yes or no)</td>
</tr>
</tbody>
</table>

### [Couple relationship]

<table>
<thead>
<tr>
<th>Activities</th>
<th>Activities done together</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>Sexual relationship</td>
</tr>
<tr>
<td>Humor</td>
<td>Using humor/telling jokes</td>
</tr>
<tr>
<td>Unit</td>
<td>Seeing the couple as unit</td>
</tr>
<tr>
<td>Gender</td>
<td>Describing differences between men and women in a relationship</td>
</tr>
<tr>
<td>History</td>
<td>Details about the couple’s history (how they met, etc.)</td>
</tr>
<tr>
<td>Othcouple</td>
<td>Relationships of other couples going through cancer</td>
</tr>
</tbody>
</table>

#### Quality of Relationship

- Happy/Good/Close: A close relationship
- Strained/distant/unhappy: A strained, distant, or unhappy relationship
- Updown: A relationship with ups and downs

### [Source of support provided to patient]

#### Family/Neighbors/Self

<table>
<thead>
<tr>
<th>Source.spouse</th>
<th>Spouse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source.kids</td>
<td>Children</td>
</tr>
<tr>
<td>Source.sib</td>
<td>Siblings</td>
</tr>
<tr>
<td>Source.othfam</td>
<td>Other family members</td>
</tr>
<tr>
<td>Source.friend</td>
<td>Friends</td>
</tr>
<tr>
<td>Source.neighbor</td>
<td>Neighbors</td>
</tr>
<tr>
<td>Source.self</td>
<td>Self-reliance/inner strength</td>
</tr>
</tbody>
</table>

#### Professional

<table>
<thead>
<tr>
<th>Source.doc</th>
<th>Doctor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source.nurse</td>
<td>Nurse</td>
</tr>
<tr>
<td>Source.MH</td>
<td>Mental health professional</td>
</tr>
</tbody>
</table>

#### Survivors

<table>
<thead>
<tr>
<th>Group</th>
<th>Cancer support group (Breakfast Club, at Siteman, church cancer group)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category</td>
<td>Source</td>
</tr>
<tr>
<td>----------</td>
<td>--------</td>
</tr>
<tr>
<td>Walk</td>
<td>Cancer walks (Sista Strut, Komen, etc.)</td>
</tr>
<tr>
<td>Individual</td>
<td>Talking with individual survivors (phone or in person)</td>
</tr>
</tbody>
</table>

**Work**
- **Work.employer**: Support from employer/boss
- **Work.routine**: Support from work routine
- **Work.role**: Support from role at work
- **Work.cowork**: Support from coworkers

**Media**
- **Intervention**: Support from Survivor Stories Intervention (video player and stories)
- **VidTV**: Support from TV, movies, or other video stories
- **Print**: Support/information from print sources: Magazines/newspapers/books
- **Internet**: Support/information from Internet (incl. FB, chat rooms, etc.)

**Religion**
- **Relig.faith**: Support through faith, belief, or God
- **Relig.pray**: Support through prayer
- **Relig.bible**: Support through reading the Bible
- **Relig.pastor**: Support from pastor
- **Relig.church**: Support from church community
- **Relig.other**: Other religious support

**Nature**
- Finding support or peace through nature

**Giving support to others**
- **Give.spouse**: Giving support or care to spouse
- **Give.child**: Giving support or care to child/children
- **Give.parent**: Giving support or care to parent(s)
- **Give.family**: Giving support or care to other family members (siblings, etc.)
- **Give.work**: Giving support to others at work
- **Give.church**: Giving support to others at church
- **Give.survivors**: Giving support to other cancer survivors
- **Give.others**: Giving support to other people not mentioned above

**Spouse’s sources of support**
- **Spouse.participant**: Support from the study participant to her husband
- **Spouse.family**: Support for spouse from family members other than patient
- **Spouse.friends**: Support for spouse from friends
Spouse.work  Support for spouse from work
Spouse.religion  Support for spouse from religion
Spouse.media  Support for spouse from print media, TV, internet, etc.
Spouse.other, none, not needed
Support from other sources, or other comments about support (incl. not wanting/needed it)

[Type of support]
Emotional  Emotional support (yes or no): talking about feelings or helping person feel understood, including “being there”
Social  Positive social interaction (yes or no): Engaging in rewarding or enjoyable activities together (e.g., going to movies, going out to eat)
Tangible  Tangible support (yes or no): Help with practical matters, such as chores or transportation to appointments
Info  Informational support (yes or no): Provision of needed information
Physical  Hugging, kissing, or other physical gestures of support (yes or no)
Gift  Giving notes, cards, flowers, gifts
Everyday  Support provided in daily life (in the absence of a major stressor)
Unwanted  Support that was unwanted or intrusive

[Telling others about cancer]
Share  Sharing news/information
Withhold  Withholding information
    Protect  Protecting others by withholding information
    Privacy  Maintaining privacy
    Strong  Needing/wanting to stay or be strong for other people

[Health, physical and mental, for participant and partner]

*Physical health of participant*
Breast cancer  Breast cancer’s effects on patient’s physical health (general)
Othcancer  Other forms of cancer (not breast cancer)
Effects  Side effects from cancer treatment from chemo, radiation, surgery, meds
Recur  Recurrence of breast cancer
Comorbid  Comorbid conditions (i.e., other chronic conditions such as diabetes)
General health  Comments about overall health (e.g., “I was healthy”)
Healthoth  Other health issues (fatigue, injury etc.)
Mental health of participant
Selfcare Caring for one’s own mental health
MI Mental illness
Addict Addiction
Stress Stress
Positive Maintaining a positive attitude
OtherMH Other mental health issue

Spouse mental/physical health
Spouse.health Spouse’s physical health: chronic conditions, other health issues, etc.
Spouse.MH Mental health of patient’s spouse (incl. stress)
Spouse.affect Cancer affecting spouse’s mental or physical health (yes or no)

Both (the couple seen as a unit in terms of health)
Both.phys Physical health
Both.MH Mental health

[Body image of participant’s body]
Image.self Self-image of body
Image.spouse Spouse’s perceptions of patient’s body
Image.other Others’ perceptions of patients’ body

[Context: Contextual factors affecting health or relationship]
Context.family Family problems, changes, stress, or other context
Context.money Money problems, changes, stress, or other context
Context.work Work problems, changes, stress, or other context (including retirement)
Context.neighborhood Neighborhood context
Context.race Description of racial isolation, discrimination, or differences
Context.health care Availability or quality of health care
Context.other Other contextual factors affecting health

[Health behavior]
Behavior.influence Couple influencing each other’s health behaviors (yes or no)
Behavior.diet Diet (either for healthy eating or weight loss)
Behavior.exercise Exercise
Behavior.doc Doctor’s visits
Behavior.doc Doctor’s visits
Behavior.vaccine Getting vaccinations
Behavior.smoking Smoking cigarettes or other use of tobacco
Behavior.other Other health behaviors
### [Advice to others with cancer]

<table>
<thead>
<tr>
<th>Advice</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>together</td>
<td>Face cancer together</td>
</tr>
<tr>
<td>expect</td>
<td>Set expectations for spouse or others</td>
</tr>
<tr>
<td>talk</td>
<td>Talk/communicate with spouse</td>
</tr>
<tr>
<td>ask</td>
<td>Ask for help from spouse if needed</td>
</tr>
<tr>
<td>notspouse</td>
<td>Lean on others besides spouse for support</td>
</tr>
<tr>
<td>doctor</td>
<td>Listen to one’s doctor</td>
</tr>
<tr>
<td>self</td>
<td>Rely on self</td>
</tr>
<tr>
<td>positive</td>
<td>Try to stay positive</td>
</tr>
<tr>
<td>depends</td>
<td>Advice depends on person/context</td>
</tr>
<tr>
<td>religion</td>
<td>Turn to God/church/faith</td>
</tr>
<tr>
<td>other</td>
<td>Any other kind of advice</td>
</tr>
</tbody>
</table>

### [Doctors help: Ways doctors and clinicians can help couples face cancer together]

<table>
<thead>
<tr>
<th>Help</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>talk</td>
<td>Talking about how cancer affects couples</td>
</tr>
<tr>
<td>materials</td>
<td>Giving written materials or other media about cancer</td>
</tr>
<tr>
<td>other</td>
<td>Other ways medical personnel can help</td>
</tr>
</tbody>
</table>
Appendix C: Information about the Medical Outcomes Study Social Support Survey

Table 8 Mean score across Survivor Stories participants for MOS-SS (Sherbourne & Stewart, 1991) items at all time points. Individual items have response items ranging from 1 to 5, where 5 indicates greater perceived social support. A copy of the MOS-SS can be found at [http://www.rand.org/health/surveys_tools/mos/mos_socialsupport.html](http://www.rand.org/health/surveys_tools/mos/mos_socialsupport.html).

<table>
<thead>
<tr>
<th>Item</th>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 3</th>
<th>Time 4</th>
<th>Time 5</th>
</tr>
</thead>
<tbody>
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<td>4.03</td>
<td>4.01</td>
<td>4.07</td>
<td>4.08</td>
</tr>
<tr>
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<td>4.41</td>
<td>4.38</td>
<td>4.41</td>
<td>4.40</td>
</tr>
<tr>
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<td>4.23</td>
<td>4.30</td>
<td>4.35</td>
<td>4.27</td>
</tr>
<tr>
<td>Item 4</td>
<td>4.47</td>
<td>4.45</td>
<td>4.46</td>
<td>4.43</td>
<td>4.36</td>
</tr>
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<td>Item 5</td>
<td>4.59</td>
<td>4.57</td>
<td>4.50</td>
<td>4.47</td>
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</tr>
<tr>
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<td>4.40</td>
<td>4.31</td>
<td>4.29</td>
<td>4.32</td>
</tr>
<tr>
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<td>4.43</td>
<td>4.31</td>
<td>4.39</td>
<td>4.31</td>
</tr>
<tr>
<td>Item 8</td>
<td>4.37</td>
<td>4.50</td>
<td>4.29</td>
<td>4.34</td>
<td>4.31</td>
</tr>
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<td>4.30</td>
<td>4.32</td>
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<td>4.09</td>
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<td>4.04</td>
</tr>
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<td>4.18</td>
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</tr>
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Figure 6. Graphical depiction of MOS-SS individual items over all five time points for Survivor Stories participants.