SEXUAL DYSFUNCTION IN YOUNG WOMEN WITH BREAST CANCER

by

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(Under the Direction of Stephanie Burwell)

ABSTRACT

Women diagnosed with breast cancer have significantly more sexual problems than healthy women without any major illness. Young women with breast cancer are especially vulnerable to sexual problems, including sexual arousal and lower frequency of sexual behaviors. These problems are often due to surgical treatment and premature menopause, psychological distress, or issues related to their relationship with their partner. This cross-sectional study examines 106 young women (aged 24-50) with breast cancer to determine the biopsychosocial correlates and predictors of sexual dysfunction. Descriptive statistics, correlations, and hierarchical regression analyses revealed that higher education ($p = .01$), more menopausal symptoms ($p = .00$), breast reconstruction ($p = .00$), and higher relationship satisfaction ($p = .01$) were the strongest predictors of sexual dysfunction. Results suggest that interventions are needed to improve psychosexual adjustment in young women with breast cancer.

INDEX WORDS: sexual dysfunction, breast cancer, medical family therapy, young women, DSM-IV-TR

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BA, Psychology, Clemson University, 2006

A Thesis Submitted to the Graduate Faculty of The University of Georgia in Partial Fulfillment of the Requirements for the Degree

MASTER OF SCIENCE

ATHENS, GEORGIA

2008

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December 2008

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CHAPTER 1

INTRODUCTION

Purpose of the Study

To date, literature on women with breast cancer has been widespread and has focused largely on biological components of the illness such as what breast cancer is, how to treat it, and its course. Psychosocial factors have been understudied, especially breast cancer's impact on family relationships (Arora et al., 2001; Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998; Meyerowitz, Desmond, Rowland, Wyatt, & Ganz, 1999; Northouse, Templin, & Mood, 2001; Speer et al., 2005). Engel's biopsychosocial model includes physiological as well as psychosocial factors, which creates a more comprehensive framework for understanding the impact of breast cancer on women (Engel, 1977). The aims of this study are twofold and are to 1) examine biopsychosocial factors associated with sexual dysfunction among women with breast cancer aged 50 and younger, and 2) determine if lower dyadic satisfaction is predictive of sexual dysfunction in younger women with breast cancer.

Breast cancer (BCA) has a great influence on the lives of many women and their loved ones (Andersen & Jochimen, 1985; Arora et al., 2001; Meyerowitz et al., 1999). Of women with cancer, 26% are diagnosed with BCA, which is a higher proportion than any other single cancer site. One out of eight women will have BCA in their lives, and one quarter of these women are younger than age 50 (American Cancer Society, 2008). The American Cancer Society estimates that there will be approximately 178,480 new invasive cases of BCA diagnosed in 2007 and over 16,000 of these women will be younger than 45. Fortunately, women are surviving breast cancer at a higher rate than in the past, as the National Cancer Institute (2007) has indicated a growing trend toward higher survival rates among young women with BCA.

Studying young women with BCA is important for several reasons. First, young women receive aggressive treatments such as radiation and chemotherapy more than other age groups (Meyerowitz, Watkins, & Sparks, 1983; Schover, 1994). As a result of aggressive treatments, fertility issues are not uncommon as young women are especially susceptible to ovarian damage or may undergo oophorectomy, or ovary removal (American Cancer Society, 2008). The National Cancer Institute (2007) reports that individuals with cancer have more treatment options, but this involves more health care spending, which can put a strain on family finances and relationships. Second, women in this stage of the life cycle will likely be at the beginning stages of living with or searching for a partner (Gould, Crassau, Manthorne, Gray & Fitch, 2006). Such unexpected illness events have been reported to disrupt quality of life in young women (Arora et al., 2001; Fobair, Stewart, Chang, D'Onofrio, Banks, & Bloom, 2006; Ganz et al., 2003; Greendale, Petersen, Zibecchi, & Ganz, 2001; Wenzel et al., 1999) as they may not be psychologically prepared for the threat of BCA (Gould et al., 2006). Finally, most studies on young women with breast cancer do not incorporate biological, psychological, *and* relational components. It is important to study each of these domains to create a more complete picture of disease and its effects on patients.

Engel (1977) originally proposed the biopsychosocial model as he believed that the dominant biomedical model overlooked psychosocial factors that are important in explaining illness. He proposed that the psychological and relational domains of illness in conjunction with the biomedical model, could better explain illness and its effect on the patient. Accordingly, disease is viewed as the biological process of a medical condition affecting the body whereas illness is defined as the process the patient goes through as the medical condition progresses that includes biological as well as contextual and relational components (Engel, 1977; McDaniel,

Hepworth, & Doherty, 1992). Many studies thus far do not include each of the major components of Engel's model. Studying sexual function from Engel's framework in this population is important because breast cancer has biological, psychological, and relational consequences for young women and their families. While the most obvious impact of breast cancer may appear to be biological due to surgical alteration and visible side effects from treatment (e.g., alopecia), psychological and relational consequences are also important, even though they may not be as visible.

Additionally, problems with sexual function among young women with breast cancer have rarely been studied or reported in conjunction with the American Psychiatric Association's (APA) Diagnostic and Statistical Manual (DSM-IV, TR) classification of sexual dysfunction (Barni & Mondin, 1997). The DSM-IV TR is used throughout the field of medicine and mental health to diagnosis psychiatric disorders including sexual dysfunction is characterized by problems related to sexual desire and psychophysiologic changes that interrupt the sexual response cycle related to sexual desire, excitement, orgasm, and resolution (APA, 2004). The manual also highlights sexual dysfunction due to general medical conditions, such as breast cancer. Sexual desire disorders such as hypoactive sexual desire disorder may occur when there is a lack of sexual desire due to the physiologic and psychological effects of breast cancer such as pain or lack of interest in sexual activity. Another problem the manual addresses is sexual arousal disorder, orgasmic disorder due to a medical condition, and sexual pain disorders, such as dyspareunia due to breast cancer. By using this classification system in the study of this population, researchers and healthcare providers will have a common language to describe and develop interventions for in young women with breast cancer (APA, 2004).

This study will use a biopsychosocial approach to identify problems related to the physiologic and psychosocial effects of breast cancer on young women. In this cross-sectional study, 106 partnered women with BCA aged 24-50 completed surveys that included measures of sexual function, relationship satisfaction, and various items describing their breast cancer, health status, and sociodemographic information. Research questions are as follows:

1) What sociodemographic, BCA, and relational factors are correlated with sexual dysfunction among women with BCA aged 50 and younger?

2) Does lower dyadic satisfaction predict sexual dysfunction in younger women with BCA above and beyond sociodemographic and BCA variables?

These questions will be addressed using multiple analytic strategies that will include descriptive statistics, correlations, and regression analyses. Results revealed that that higher education, more menopausal symptoms, breast reconstruction, and higher relationship satisfaction were the strongest predictors of sexual dysfunction. Finally, implications for marriage and family therapists and other health care providers will be provided.

CHAPTER 2

LITERATURE REVIEW

Young women with BCA face many challenges including problems related to sexual function (Barni & Mondin, 1997; Broeckel, Thors, Jacobsen, Small, & Cox, 2002; Ganz et al., 1998; Ganz et al., 2003; Winer, Lindley, Hardee, Sawyer, Brunatti, Borstelmann, & Peters, 1999). According to the American Cancer Society, young women are defined as aged 50 and younger (American Cancer Society, 2008). In addition to the American Cancer Society, the North American Menopause Society who publish the journal *Menopause* use 50 as a cut-off for young women because 50-51 is the mean age for onset of menopause in healthy women (Gold, Bromberger, Crawford, Samuels, Greendale, Harlow, & Skurnick, 2001). Women diagnosed with BCA have significantly more sexual problems than healthy women without any major illness (Ganz et al., 1998; Meyerowitz, Desmond, Rolland, Wyatt, & Ganz, 1999). Women with BCA experience problems with sexual arousal and less frequency of sexual behaviors as a result of surgical treatment and premature menopause, psychological distress (e.g., depression or anxiety), or issues related to their relationship with their partner (Andersen & Jochimsen, 1985; Winer et al., 1999). A study conducted by Ganz and colleagues (1998) of 864 women with BCA found that the young women reported more menopausal symptoms (e.g., hot flashes or headaches) than healthy samples with a similar age distribution. Another cross-sectional study using the same sample of 863 BCA patients diagnosed within the past five years found that BCA had a negative impact on one third of the women's sex lives (Meyerowitz et al., 1999). Likely, these numbers would have been higher if the sample had been limited to women more recently diagnosed and in active treatment.

Factors related to the sexual function of younger women with BCA can be understood using Engel's (1977) biopsychosocial model. His model includes biological, psychological, and relational factors. As outlined in Engel's model, these domains will be used to organize the literature review and provide a theoretical framework to guide the research questions to better understand sexual dysfunction in young women with BCA.

Biological Factors

Many of the usual treatments for BCA have side effects that have consequences for sexual function and include chemotherapy, radiation, hormone therapies, and surgical treatments such as mastectomy, lumpectomy, and breast reconstruction (Anllo, 2000; Arora et al., 2001; Bransfield, 1982; Broeckel et al., 2002; Fobair et al., 2006; Ganz et al., 1998; Ganz et al., 1999; Lindley et al., 1998; Rogers & Kristjanson, 2002; Rowland et al., 2000; Schover, 1991; Schover, 1994; Young-McCaughan, 1996). BCA patients often experience a variety of side effects such as alopecia (hair loss) or weight changes due to cancer and its treatment that have bearing on sexuality (Fobair et al., 2006; Young-McCaughan, 1996). Side effects can be acute or chronic and last anywhere from a few days to years or a lifetime. For example, alopecia is usually temporary while menopause is chronic (Fobair et al., 2006). Not only is it important for patients to understand BCA treatments and their side effects, but it is also important for partners to be sensitive toward treatment effects (Burwell, Templeton, Kennedy, & Zak-Hunter, 2008; Walsh, Manuel, & Avis, 2005). Increased understanding can help patients and partners deal with these biological effects to minimize, diminish, or eliminate sexual problems resulting from BCA (Anllo, 2000; Barni & Mondin, 1997; Wimberly et al., 2005).

Some of the biological factors that have been studied in regard to BCA and sexual function include treatment type, medication and cancer stage (Anllo, 2000; Arora et al., 2001;

Ganz et al., 1998; Ganz et al., 1999; Schover, 1991; Schover, 1994). Young women often face stressors older women may not face such as problems with fertility brought about by early menopause (Ganz et al., 2003; Northouse, 1994; Stead, 2003). Young women have also reported poorer mental health (e.g., depression) and vitality due to their BCA diagnosis (Ganz et al., 2003; Northouse, 1994; Wenzel et al., 1999; Yurek, Farrar, & Andersen, 2000). Young women with BCA also have trouble adjusting to BCA and worry about disease reoccurrence (Northouse, 1994; Schover et al., 1995; Wenzel et al., 1999). Regarding surgery, young women opt for mastectomy less, reconstructive surgery including nipple and breast reconstructive surgery more, and have more frequent sexual activity than older women diagnosed with BCA (Schover et al., 1995; Wolber et al., 1987).

Chemotherapy and radiation have been shown to have numerous and severe side effects that vary depending upon the patient characteristics and length of time she has been undergoing treatment (Brandberg et al., 2003; Dow & Lafferty, 2000; Kornblith et al., 2003; Lindley et al., 1998; Winer et al., 1999; Young-McCaughan, 1996). Women who have chemotherapy or radiation often experience far more sexual problems than those who do not undergo these treatments (Berglund, Nystedt, Bolund, Sjoden, & Rutquist, 2001; Brandberg et al., 2003). Other symptoms that have been associated with chemotherapy include premature menopause, fatigue, constipation, nausea, vaginal dryness, reduced libido from estrogen deficiency, female orgasmic disorder, and pain with vaginal intercourse (Anllo, 2000; Arora, Gustafson, Hawkins, McTavish, Cella, Pingree, Mendenhall, & Mahvi, 2001; Barni & Mondin, 1997; Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998; Lindley, Vasa, Sawyer, & Winer, 1998; Rogers & Kristjanson, 2002; Young-McCaughan, 1996). These symptoms often overlap criteria for hyposexual desire disorder (lowered desire for sexual activity), dyspareunia (pain associated with intercourse), or

female orgasmic disorder (APA, 2004). Premature menopausal symptoms can be especially traumatic among younger women as these can include fatigue, difficulty with bladder control, vaginal dryness, pain with sex, hot flashes, issues with fertility (e.g., ovarian failure), and amenorrhea (Anllo, 2000; Greendale, Petersen, Zibecchi, & Ganz, 2001; Rogers & Kristjanson, 2002; Schover, 1991; Thors, Broeckel, & Jacobsen, 2001).

In a cross sectional study of 153 women aged 40 and above (average age of 45 at time of diagnosis) who were treated with chemotherapy for BCA over 20 years ago, 29% were still experiencing sexual problems (Kornblith et al., 2003). These symptoms can have direct effects on sexual function such as vaginal dryness or a burning sensation during intercourse, but indirect effects such as fatigue or hot flashes may also lead to problems with sexual function. In another cross-sectional study of 67 women (Young-McCaughan et al., 1996), those undergoing chemotherapy were 6.5 times more likely to report weight changes, 3.6 times more likely to report hot flashes, 6.5 times more likely to report mood swings, and 5.7 times more likely to report vaginal dryness. These effects were highly correlated with sexual dysfunction in these women with the possibility of decreased libido three times more likely and dyspareunia 5.5 times more likely.

Fertility can also be an important concern for younger women as chemotherapy has been associated with ovarian damage and/or failure (Rogers & Kristjanson, 2002; Schover, 1991; Thewes et al., 2004). Ovarian failure is especially common among women over 40. An increasing number of women today are delaying pregnancy, and childbirth is increasing in women over 40 after having chemotherapy. Because the ovaries produce 50% of the body's androgen which promotes sexual desire, less androgen will be produced and sexual desire will be lowered if the ovaries are damaged (Schover, 1994).

Sometimes women must take endocrine or hormonal therapies such as Tamoxifen to treat premenopausal symptoms. Side effects from hormonal therapies include vaginal atrophy or dryness, problems of desire, and pain or burning with intercourse (Anllo, 2000; Ganz, Rowland, Meyerowitz, & Desmond, 1998; Schover, 1994; Greendale, Hogan, & Shumaker, 1996; Mortimer, Boucher, Baty, Knapp, Ryan, & Rowland, 1999). Mortimer and colleagues (1999) studied Tamoxifen's effect on sexual functioning cross-sectionally among 57 breast cancer patients aged 36-84, and found that 54% experienced pain, burning, or discomfort with intercourse. Most patients' experiences were linked to vaginal dryness or discomfort (Mortimer et al., 1999).

Patients receiving a mastectomy or partial mastectomy have reported increased sexual dysfunction (Arora et al., 2001; Moyer, 1997; Rowland et al., 2000; Schain et al., 1993). Although young women typically experience more frequent sexual activity and sexual desire than women over 50 after mastectomy or partial mastectomy, they still show significant problems with sexual activity such as dyspareunia, vaginal dryness, and pain with intercourse (Arora et al., 2001; Schover et al., 1995; Wenzel et al., 1999). These effects are most often short term and due to problems associated with surgery such as fatigue or tenderness of the breast. Young women more often opt for reconstructive surgery after mastectomy or partial mastectomy, which involves additional recovery time (Schover et al., 1995; Schover et al., 1994). For example, Kemeny and colleagues (1988) studied effects of surgery type (mastectomy versus segmentectomy (a less invasive surgery) longitudinally at 6 months and approximately 12 months post surgery by surveying 52 women aged 36-72 with Stage I or II breast cancer. Most women thought mastectomy was more traumatic at 6 months post-treatment than long-term (12 months). In a cross-sectional study by Rowland and colleagues (2000) surveying nearly 2000

breast cancer patients revealed that women undergoing mastectomy experienced far more physical symptoms related to their surgery than lumpectomy patients. Patients receiving invasive surgery are often too fatigued to engage in sexual activity until healing occurs (Schain, D'Angelo, Dunn, Lichter, & Pierce, 1994). However, some effects may be more long term and are more likely linked to psychological factors such as a negative body image or feeling uncomfortable in the nude, and are discussed further in the section on psychological factors (Anllo, 2000; Arora et al., 2001; Moyer, 1997).

Clearly BCA and its treatment have biological short and long-term effects on sexuality and sexual function. By recognizing these effects, the DSM-IV-TR (APA, 2004) can be helpful in classifying the patient's sexual issues due to BCA, and can also provide a common language for healthcare providers who provide treatment to this population. Pain, fatigue, hot flashes, and other symptoms mentioned as biological effects of BCA are symptoms of dyspareunia, which is characterized by genital pain, insufficient vaginal lubrication, or other pain associated with intercourse. In addition, the pain and fatigue may also influence desire for sexual activity, thereby characterizing hypoactive sexual desire disorder, which emphasizes persistent absence of sexual desire that causes significant distress (APA, 2004). By understanding and classifying sexual effects from BCA treatments, healthcare providers can work collaboratively to recommend and implement appropriate treatments to alleviate symptoms.

Psychological Factors

BCA has a profound impact on a patient's psychological well-being and consequently, on sexuality (Fobair, Stewart, Chang, D'Onofrio, Banks, & Bloom, 2006). The fear of death, treatment related concerns, loss of breast(s), loss of ovarian function, uncertainty about the future, and death and dying are only a select number of concerns that impact women with BCA.

These concerns can evoke a range of responses and exacerbate anxiety, depression, and post traumatic stress symptoms (Kornblith et al., 2003; Schover, 1991; Wenzel et al., 1999). Many of the surgeries and treatments associated with BCA, such as mastectomy, can influence body image and femininity (Anllo, 2000; Arora et al, 2001; Bransfield, 1982; Moyer, 1997; Schover, 1994; Stead, 2003; Thors, Broeckel, & Jacobsen, 2001). Premature menopausal symptoms can be especially traumatic for young women because they are not expecting these changes at this stage in their life cycle (Greendale, Hogan, & Shoemaker, 1996; Wilmoth, 2001). Overall, there is an inverse relationship for age at diagnosis and emotional distress such that younger women have more emotional distress than older women (Anllo, 2000).

Women who are highly depressed or anxious may have problems related to sexual function that were not present before BCA (Al-Ghazal, Fallowfield, & Blamey, 2000; Fobair et al., 2005; Ganz et al., 1999; Wolber et al., 1987). Women undergoing mastectomy showed higher rates of anxiety, depression, and posttraumatic stress disorder symptoms (e.g., disease-intrusive thoughts after surviving breast cancer) than those without cancer or not undergoing invasive surgery (Kornblith et al., 2003; Schover, 1991; Wenzel et al., 1999; Wolberg, Tanner, Romsaas, Trump, & Malec, 1987). In a cross-sectional study of 206 women with BCA measuring differences between treatment types, Wolberg and colleagues (1987) found that BCA patients undergoing mastectomy were significantly more anxious, introverted, depressed/dejected, and had more sexual problems than women who chose breast conservation surgery.

Many women see benefits from breast reconstructive surgery after mastectomy including better psychological adjustment, feeling more feminine, and having better sexual functioning (Al-Ghazal, Fallowfield, & Blamey, 2000; Schover, 1991). Those opting for breast

reconstruction tend to be younger and show more concern with body image in general (Schover, 1994; Thors, Broeckel, & Jacobsen, 2001). This group shows more positive feelings about their bodies, especially in the nude and has the benefit of being able to wear more types of clothes and avoid wearing prosthesis (Schover, 1991; Schover, 1994; Thors, Broeckel, & Jacobsen, 2001; Wapnir, Cody, & Greco, 1999). In a retrospective, cross-sectional study by Al-Ghazal and colleagues (2000), 121 women having immediate versus delayed breast reconstruction were assessed for anxiety, depression, body image, self-esteem, and sexuality at follow-up appointments after treatment. They found that 95% of the immediate construction group preferred their treatment and 76% of the delayed reconstruction group would have preferred immediate reconstruction. The immediate reconstruction group showed decreased anxiety and depression and increased body image, self-esteem, and sexual feelings of attractiveness and satisfaction (Al-Ghazal, Sully, Fallowfield, & Blamey, 2000).

Studies also suggest women undergoing breast-conserving surgery such as lumpectomy were less stressed, anxious, and depressed (Moyer, 1997; Schover, 1991). In Moyer's (1997) meta-analysis of 40 articles on breast-conserving surgery versus mastectomy, he found that women having breast-conserving surgery showed better psychological adjustment including less anxiety and depression following surgery. In a cross-sectional study of 577 women having either wide local excision, simple mastectomy, or breast reconstruction, those women with wide local excision followed by breast reconstruction showed the most positive results with psychological morbidity including anxiety, depression, body image, sexuality, and self-esteem (Al-Ghazal, Fallowfield, & Blamey, 2000). Most decreases in sexual dysfunction due to breast-conserving surgery were due to short-term, biological factors associated with surgery such as pain and fatigue during the recovery process (Moyer, 1997).

Women with lumpectomy also showed less fear and concern with the cancer itself and were more self-interested and valued their appearance more than BCA patients who had a mastectomy (Moyer, 1997; Wolberg et al., 1987). Women worried less about their clothes fitting, wearing a prosthesis, body image, or maintaining a sexual relationship (Moyer, 1997; Schover, 1991; Schover, 1994). In a review of the literature (Schover, 1994), women opting for breast conservation showed more positive feelings about their bodies, especially in the nude. Before surgery, this group of women showed concern about body image in general. Schover (1994) also found that women with less extensive surgery felt more attractive and sexually desirable than those who had a mastectomy without reconstruction. Rowland and colleagues (2000) studied almost 2000 women with breast cancer and their physical and emotion outcomes 1-5 years after surgery in a cross-sectional study. Lumpectomy patients showed the most positive body image and feelings of attractiveness after their treatment, which gives strength to the argument that less invasive surgeries have better emotional and body image outcomes for BCA patients seeking treatment. Finally, in a cross-sectional study of 190 women with breast cancer (Yurek, et al., 2000), the breast conserving treatment group had intercourse more frequently following treatment and experienced greater arousal during sexual activity compared to women having a mastectomy. They also had more orgasms, feelings of satisfaction during sexual experiences, and the lowest body change distress.

Some of the more invasive breast cancer treatments (e.g., mastectomy) may cause patients to feel less feminine, especially after the loss of a breast(s), which can have a significant impact on body image (Anllo, 2000; Arora et al., 2001; Wilmoth, 2001). During chemotherapy, women may lose their hair or experience weight gain—both of which greatly influence body image and feelings of femininity (Rogers & Kristjanson, 2002). After mastectomy, women have

also reported difficulty allowing their partner to see them in the nude because of their scarring and altered breast(s) (Bransfield, 1982; Schover, 1994; Wilmoth, 2001), and this negative self-image has led to more sexual difficulties (Stead, 2003).

Chemotherapy can cause major damage to the ovaries, which may have psychological effects on BCA patients (Schover, 1991; Schover, 1994). Some younger women feel a sense of femininity by knowing they are fertile and can bear children if they desire. For example, in one study as many as 89% of women undergoing chemotherapy had some damage to their ovaries during the treatment (Anllo, 2000). Chemotherapy has been linked with ovarian failure and premature menopause, which can have an effect on the ability to bear children (Schover, 1991). Young women experience extra difficulties associated with the loss of reproduction functioning and relationship issues (Stead, 2003). In a qualitative study of 18 women with breast cancer, Thewes and others (2004) found that many young women were distressed about their treatment's possible effect on their fertility. Women with a more negative sexual self-image were more likely to experience sexual difficulties and cope with changes in sexual function (Stead, 2003). A lack of feeling feminine, whether from loss of breasts or fertility, can effect how a woman defines herself as a woman, child bearer, or sexual partner.

Many women in chemotherapy, radiation, or hormone therapy experience premature menopausal symptoms, and these symptoms have been linked to poorer sexual functioning and lower psychological well-being (Greendale, Hogan, & Shoemaker, 1996). In a longitudinal study by Berglund and colleagues (2001) of 293 women with BCA (assessments taken after surgery to 3 years post-surgery at 7 time points), patients with chemotherapy treatment had significantly higher levels of sexual dysfunction than those with no systemic treatment. Smaller studies of sample sizes under 100 (72 and 67, respectively) also confirmed this finding (Schover et al.,

1995; Young-McCaughan, 1996). Many women did not feel ready for these menopausal changes (e.g., hot flashes) from radiation and chemotherapy and reported it affected their feelings of attractiveness and consequently felt emotionally distressed (Arora et al., 2001; Fobair et al., 2006; Wilmoth, 2001).

After chemotherapy, women were more likely to have a negative body image, negative affect, negative psychological symptoms, and decrease of general sexual function (Young-McCaughan, 1996). These premenopausal symptoms due to chemotherapy and radiation treatment were associated with poorer health perceptions (Ganz, Greendale, Petersen, Kahn, & Bower, 2003). In a cross-sectional study of 549 women aged 22-50 in a married or stable relationship, Fobair and colleagues (2006) surveyed women about their body image and sexual adjustment involving breast cancer. They found that 50% of these partnered women showed two or more body image issues some of the time and one body image issue "much of the time." They also found that more sexual problems were correlated with poor mental health and problems with body image. Those with poorer perceived health were associated with less sexual interest (Greendale et al., 2001).

As cited, symptoms of anxiety, depression, fear, negative body image, and PTSD can lead to problems with sexual function (Barni & Mondin, 1997). Problems of sexual desire and arousal may be especially prevalent in young women with BCA as marked by low or deficient ability to have desire for sexual activity or ability to become aroused or maintain arousal during sexual activity as outlined in the DSM-IV TR (APA, 2004). Health care providers should be aware that BCA can affect sexual function both biologically and psychologically.

Relational Factors

Social effects of BCA on the patient and partner involve many aspects of their lives including but not limited to the community, health care providers, familial support, friends,

coworkers, and churches (Northouse, 1984; Northouse, 1988; Northouse, 1996; Rolland, 1999; Thewes et al., 2004). Most research on sexuality has concentrated on partners and health care providers (Ganz et al., 1999; Northouse & Northouse, 1988; Takahashi & Kai, 2005; Thewes et al., 2004; Wilmoth, 2001; Wimberly et al., 2005). Social or relational factors may exacerbate or help to buffer some of the hardships women and their partners experience with BCA (Northouse, 1988; Northouse, 1996; Thewes et al., 2004). For example, neighbors who provide instrumental help to do lawn work or bring dinners to the patient may help to alleviate distress associated with fulfilling daily household labor (Anllo, 2000).

Breast cancer can be a life-changing illness, and many patients experience changes in their relationship with their partner (Anllo, 2000; Barni & Mondin, 1997). Nearly one third of BCA patients separate or divorce following BCA diagnosis (Meyerowitz et al., 1999; Walsh, Manuel, & Avis, 2005). In a cross-sectional study of 50 women aged 20-65 years old who had some type of surgery due to BCA, Barni and Mondin (1997) discovered approximately 50% of these women reported some negative change in their relationship with their partner due to BCA. In another qualitative study, Thewes and colleagues (2004) asked 18 women with BCA about their relationship with their partner following diagnosis. The majority of the women talked about the major negative impact diagnosis had on their partner (e.g. increased stress), and consequently on their sexual relationship.

Not all sexual effects are due to BCA alone. Oftentimes preexisting factors such as low marital satisfaction or previous sexual dysfunction contribute to sexual dysfunction following BCA diagnosis (Anllo, 2000). A study described earlier by Ganz et al. (1999) surveyed 863 BCA survivors about their sexual health using the Revised Dyadic Adjustment Scale (RDAS), Cancer Rehabilitation Evaluation System (CARES) and the 32-item Mental Health Index from the

Medical Outcomes Study (MOS) and found that the quality of the partner relationship influenced sexual satisfaction such that the better the relationship, the better the sexual satisfaction. On the other hand, sexual problems brought on by the BCA treatment sometimes had a negative impact on the relationship (Meyerowitz et al., 1999). Therefore, dyadic satisfaction and sexuality following treatment for BCA can be seen as having a bidirectional influence on one another. Following is a brief summation of the research concerning the partner's effects on BCA patient sexual function.

Partner Factors

Studies have shown that relational variables play a role in sexual function among women with BCA (Ganz et al., 1999; Northouse & Northouse, 1988; Takahashi & Kai, 2005; Thewes et al., 2004; Wilmoth, 2001; Wimberly et al., 2005). Open communication between patient and partner has been linked to better quality of life and adjustment, including sexuality (Anllo, 2000; Schover et al., 1995). In an aforementioned cross-sectional study on body image and sexual problems in younger women with BCA, Fobair et al. (2006) interviewed and surveyed 549 women aged 22-50 in a married or committed relationship. They found that the partner's difficulty in understanding the patient's feelings was correlated with more sexual problems. Marital and sex therapy was suggested for these couples to help assist with communication about BCA and sexuality (Fobair et al., 2006; Meyerowitz et al., 1999; Yurek, Farrar, & Andersen, 2000).

In an illness such as BCA, the patient may worry how her partner will feel about the treatment options and experience fears of abandonment (Anllo, 2000; Wilmoth, 2001). A life-changing illness may bring to the surface doubts of the partner's willingness to stay in the relationship. In one review, women indicated that they were worried that their partner may

abandon them for someone who is healthier and who can perform better sexually (Anllo, 2000). Patients who were in unhappy or unstable marriages wanted to stay in their relationship because they did not want to feel alone (Wilmoth, 2001). For some, a BCA diagnosis serves as an impetus for a patient or partner to leave a troubled relationship (Walsh et al., 2005).

The quality of the partner relationship and partner sexual problems influence patient sexual function (Ganz et al., 1999; Takahashi & Kai, 2005). In a qualitative study by Takahashi and Kai (2005), 21 Japanese women with BCA stated that their partners had become hesitant to have sex because of various reasons surrounding BCA such as discomfort viewing their partner's scar or fear of hurting their partner. Partners who were more involved in decision making related to BCA treatment had higher levels of sexual satisfaction post treatment (Bransfield, 1982; Takahashi & Kai, 2005).

Oftentimes, partners' response to BCA treatment has an effect on the sexual relationship. Compared to single women, those women who had partners were less likely to be embarrassed and worry about their sexual attractiveness (Fobair et al., 2006). Wimberly and other researchers (2005) examined 170 patients and their perceptions of their partners' reactions to BCA. They found that partners who initiated sex predicted greater marital and sexual satisfaction after surgery, and if the first initiation of sex was positive, then psychosexual health was more positive and the patient showed less emotional distress concerning sexual function. However, specific to those patients who received a mastectomy, partners who had a negative reaction to a patient's scar after surgery predicted less sexual satisfaction. In general, engaging in sexual activity after treatment was influenced by importance of sexual relationship and fear of partners' response (Takahashi & Kai, 2005).

In sum, young women with BCA face potential problems related to relationship satisfaction and sexual function (Barni & Mondin, 1997; Broeckel, Thors, Jacobsen, Small, & Cox, 2002; Ganz et al., 1998; Ganz et al., 2003; Winer, Lindley, Hardee, Sawyer, Brunatti, Borstelmann, & Peters, 1999). Women diagnosed with BCA have significantly more sexual problems than healthy women without any major illness (Ganz et al., 1998; Meyerowitz, Desmond, Rolland, Wyatt, & Ganz, 1999). This occurs for a variety of reasons outlined by the biopsychosocial model including symptoms related to surgical treatment and menopause, psychological distress, or issues related to their relationship with their partner (Andersen & Jochimsen, 1985; Engel, 1977; Winer et al., 1999). This theoretical framework guided the research questions in understanding what proportion of variance sexual dysfunction in young women with BCA can be account for by relational variables above and beyond sociodemographic and BCA variables.

CHAPTER 3

METHODS

Research Questions

This study will use an existing data set to address the following research questions:

1. What sociodemographic, BCA, and relational factors are correlated with sexual dysfunction among women with BCA aged 50 and younger?
2. Does lower dyadic satisfaction predict sexual dysfunction in young women with BCA above and beyond sociodemographic and BCA variables?

Sample

Several recruitment methods were used to accrue study participants (n = 106) for the larger study, conducted by Dr. Stephanie Burwell. Women were primarily recruited through online BCA sites such as the Susan Komen Foundation, local BCA support groups and breast clinics, local newspaper advertisements, Relay for Life, study advertisements in the local chapter of the American Cancer Society newsletter, and flyers to participate in the original study entitled, "Couples Coping with Breast Cancer." Inclusion criteria were that women be between 18-50 years of age, diagnosed with BCA within the past three years, have no previous breast or any other type of cancer, have a husband or partner with no major medical condition, have had the same spouse or partner since the time of diagnosis, and be able to provide informed consent.

Procedure

The "Couples Coping with Breast Cancer" study was approved by the Institutional Review Board for the following data analysis (IRB; see Appendix). A cross-sectional survey was comprised of items and questions concerning demographic data, BCA health, sexual function, and dyadic satisfaction. Participants completed a survey that was mailed or taken online using

Survey Monkey, a secure online site for survey research: http://www.surveymonkey.com/s.aspx?sm=JH0_2fz_2fJ6jpD61NhLzM5Kdw_3d_3d Online participants were entered in a drawing for a $50 gift card. Participants not recruited online were compensated $15 for completing the hard copy of the survey. Participants remained anonymous and only gave their information if they wanted to participate in the drawing and future studies involving BCA patients. Each participant was assigned a random identification number to ensure anonymity.

Measures

The measures and items relevant to these analyses are described below beginning with the dependent variable. All measures are included in the Appendix.

Sexual dysfunction. The 4-item Medical Outcomes Study (MOS) Sexual Problems Subscale measures sexual interest, arousal, ability to relax and enjoy sex, and ability to achieve orgasm (Sherbourne, 1998). Responses are on a 4-point Likert scale and include, "strongly agree", "agree", "neither agree nor disagree", "disagree" and "strongly disagree". A mean score was obtained from these 4 items and transformed to a 0-100 scale with lower scores indicating less sexual problems. Internal consistency reliability for this measure was 0.92, and this measure has good overall psychometric properties including high construct and predictive validity (Broeckel et al., 2002; Sherbourne, 1998). The Cronbach Alpha for the measure in this study is .83. In addition to the dependent variable (MOS), participants were asked if they had been "sexually active" in the past month (yes/no) as an independent variable. There are no psychometric properties available for this question.

Biological variables. These variables were cancer stage (I-IV), surgical and adjuvant treatments including lumpectomy, mastectomy, reconstruction, chemotherapy, radiation, and

endocrine therapy (yes/no), current health perception ("much better now than before cancer," "somewhat better now than before cancer," "about the same," "somewhat worse now than before cancer," and "much worse now than before cancer"), and in current treatment (yes/no). Current symptoms (e.g., hot flashes, nausea, and vomiting) were measured on a 5-point Likert scale that assessed if the symptom had bothered them in the past 4 weeks and responses ranged from "not at all" to "very much". No information on validity or reliability was available, but the Cronbach Alpha for symptom severity in this study was .71. These symptoms were broken down into two sum scores: one for menopausal symptoms and one for other symptoms. Menopausal symptoms included nausea, hot flashes, difficulty with bladder control, vaginal dryness, and pain with sex. Other symptoms included diarrhea, nausea, vomiting, vaginal discharge, general aches and pains, swelling of hands and feet, unhappiness with the appearance of one's body, and weight change (gain/loss). Finally, time since diagnosis (measured in months) was calculated. Symptom severity and treatment/surgery types are presented in the Appendix.

Psychosocial Variables. Relationship satisfaction comprised the psychosocial variable and was measured by the Revised Dyadic Adjustment Scale (R-DAS) (Busby, Christensen, Crane, & Larson, 1995). This 14-item measure explores the level of agreement between partners concerning different topics (e.g., religious preferences of demonstration of affection). There are seven response choices ranging from "always agree" to "always disagree". Scores can be summed and dichotomized as "distressed" and "not distressed" using a cutoff score of 48 or used as a continuous sum score. Lower scores indicate distress and higher scores indicate less distress. This scale has strong convergent and criterion validity, and has been compared to other measures of dyadic satisfaction such as the Locke-Wallace Marital Adjustment Test (Busby, Christensen, Crane, & Larson, 1995). The internal consistency for the R-DAS is .92 overall (Cronbach alpha

= .92 for this study), and .86 for the Cohesion Subscale, .83 for the Consensus Subscale, and .90 for the Satisfaction Subscale (Busby et al., 1995).

Sociodemographic variables. Categorical variables included education level (ranging from no formal education to doctoral degree), ethnic/racial background (white, African-American, Hispanic/Latino, American Indian or Alaskan Native, Asian or Pacific Islander, or Other), marital status (married versus partnered), divorce history (previous divorce vs. not), income, health insurance (yes/no), and work status (full-time, part-time, stopped working due to ill health, retired, never in paid employment, unemployed and searching for work, student, or other). Continuous variables were patient age and number of children.

Analyses

Analytic Strategy for Question 1: What sociodemographic, BCA, and relational factors are correlated with sexual dysfunction among women with BCA aged 50 and younger?

Data were entered and analyzed using the Statistical Package for the Social Sciences 15.0 (SPSS). Descriptive statistics determined the frequencies, means, and standard deviations of all variables. The independent variables in this analysis are the biological, sociodemographic, and relational variables. The dependent variable is sexual dysfunction as determined by the MOS Sexual Problems Subscale. Higher scores indicate more sexual problems. This subscale was transformed into a score ranging from 0 - 100 using an algorithm given by Stewart, Hays, and Ware (1998) as follows:

$$\frac{100 \times (\text{observed score} - \text{min. possible score})}{(\text{maximum possible score} - \text{min. possible score})} =$$

$$\frac{100 \times (\text{mostotal} - 1)}{3} =$$

100 x MOSTOTALpretran = MOSTOTALTRANSFORMED (0 to 100)

Next, correlations were performed to examine the degree of association between sociodemographic, biological, and relational variables and sexual dysfunction using Pearson's product moment correlation analysis for two continuous variables. Pearson point-biserial correlations were used to determine the association between one continuous and one dichotomized variable (Cohen, Cohen, West, & Aiken, 2002; Newman, 2006). The dependent variable, sexual dysfunction, was examined by domain (interest, arousal, orgasm, ability to relax/enjoy sex) as well as total score. Effect sizes of .3 or stronger were considered meaningful among all correlations (Cohen et al., 2002; Green & Salkind, 2008), as values further away from 0 indicated greater association with measures of sexual dysfunction (Newman, 2006).

Analytic Strategy for Question 2: Does lower dyadic satisfaction predict sexual dysfunction in young women with BCA above and beyond sociodemographic and BCA variables?

A hierarchical regression analysis was run to determine the relative contributions of sociodemographic factors, BCA variables, and relationship satisfaction (measured by the R-DAS) as predictors of sexual dysfunction. This type of regression was informed by biopsychosocial theory and best fits the research question so that the affects of sociodemographic, BCA, and relational variables can be entered in one group at a time to see how much each block of variables contributes to the variance in sexual function. The research question asked the proportion of variance accounted for in relational variables when controlling for sociodemographic and breast cancer variables, so this block was entered last. Sociodemographic variables were entered first because these are temporally prior to BCA diagnosis and most unlikely to measure the proportion of variance accounted for in BCA. BCA

variables were entered in the second block to account for the proportion of variance of biological variables before the addition of relational variables. Finally, relational variables were entered last so that the possible effect of sociodemographic and BCA variables could be controlled for to see if it is still able to predict a significant portion of the variance in sexual dysfunction over and above sociodemographic and relational variables (Cohen et al., 2002; Pedhazur, 1997).

The independent variables included in the regression analysis were determined from the correlation procedures described above. All categorical variables were dummy coded as "0" or "1" (e.g., marital history will be coded as previous divorce = 1, separation = 0, marriage = 0 to measure divorce rate). All dichotomized variables are presented in Table 1. Correlations with an effect size of .3 or larger were included in the regression model (Green & Salkind, 2008). After meaningful correlations were determined, the independent variables were then entered into the regression model in three steps: 1) sociodemographic variables, 2) BCA variables, and 3) relational variables. The biopsychsocial model guided the grouping and order of entry of the independent variables into the regression model to determine their specific contributions in predicting sexual dysfunction (Grimm & Yarnold, 1995).

CHAPTER 4

RESULTS

The purpose of this study was to examine factors correlated with sexual dysfunction among women with BCA and to determine if lower dyadic satisfaction predicts sexual dysfunction above and beyond sociodemographic and BCA variables in young women with breast cancer from a biopsychosocial lens (Engel, 1977). The results are divided into three sections and guided by the research aims. Section one provides results pertaining to descriptive statistics, the second focuses on correlations between biopsychosocial variables and sexual dysfunction, and the third section presents results from the hierarchical regression analysis.

The Statistical Package for the Social Sciences 15.0 (SPSS) was used to manage and analyze data. Descriptive statistics determined frequencies, means, and standard deviations for all variables. Pearson and Pearson point-biserial correlations were run between independent variables to control for collinearity. Additional correlations were run between independent variables and the dependent variable to determine the strength of relationship for inclusion in the regression analysis. Hierarchical regression analysis determined predictors of sexual dysfunction in younger women with BCA.

Participant Characteristics

The analytic sample included 106 women and their participant characteristics are presented in Table 2. The majority of the participants in the sample were white (93%), middle to upper class (59% of participants had a combined income of $75,000 or above), and completed higher education (58% were college graduates). Almost all women reported having health insurance (99%). Approximately 84% of women reported they were married (vs. partnered), and 79% of the sample had children. On average, women were age 41 (SD = 7.02), partners were age

42 (SD = 7.85), and patients reported being in their current relationship for 12.85 years (SD = 8.56).

In characterizing the sample in terms of breast cancer diagnosis and treatment, women were diagnosed approximately 11.84 months post-diagnosis (SD = 9.61), and 73% of women were in current cancer treatment at the time they completed the survey. Of the women who reported cancer stage (n = 21), women were in stage II breast cancer on average (SD = .45). Regarding treatment, 76% of women underwent chemotherapy, 63% had radiation, 57% had hormone therapy, and 42% reported undergoing other treatment. In terms of surgery, 55% had mastectomy, 72% had lumpectomy, 40% had reconstructive surgery, and 82% had auxillary node dissection. Finally, menopausal symptom severity (low to high) was obtained by a sum score (ranging from 6-30) with a mean of 12.12 (SD = 4.36). These sociodemographic and breast cancer descriptive statistics show that the sample was fairly homogenous (white, middle to upper class, high level of education) and the sample was fairly evenly distributed in terms of breast cancer variables.

Research Question 1: Frequencies and Correlations

Question 1: What sociodemographic, BCA, and relational factors are correlated with sexual dysfunction among women with BCA aged 50 and younger?

Means and standard deviations of the independent variables are summarized in Table 3. Of the analytic sample, 69% of women reported being sexually active during the past month. The MOS Sexual Problems Subscale is reported by the transformed total score and by domain. The MOS Total Score ranged from 0-100 where higher scores indicated better sexual function, and was somewhat equally distributed across the range. Almost half of the sample reported problems

with sexual function in at least one domain (interest: 65.1%, arousal: 57.5%, orgasm: 44.3%, or ability to relax/enjoy sex: 47.1%) and are also summarized in Table 3.

Correlation coefficients were first computed among the following independent variables: patient age, months in relationship, marital status, divorce history, number of children, months since diagnosis, education, income, work status, menopausal symptoms, other symptoms, treatment types, surgery, in current treatment (yes/no), current health perception, cancer stage, sexual activity in the past month (yes/no), and the RDAS total score. Education, income, work status, current health perception, divorce history, treatment, and surgery types were dichotomized to be entered as Pearson point-biserial correlations (presented in Table 1). Variables with correlations of .3 or higher were flagged as meaningful and were included for consideration in the subsequent regression analyses and include: mastectomy and lumpectomy (r = -.49), breast reconstruction and lumpectomy (r = -.30), chemotherapy and auxillary node dissection (r =.67), radiation therapy and auxillary node dissection (r =.38), in current treatment and cancer stage (r = -.39), breast reconstruction and mastectomy (r =.82), radiation therapy and hormone therapy (r =.57), months since diagnosis and radiation therapy (r =.47), months since diagnosis and hormone therapy (r =.44), menopausal symptoms and other symptoms (r = .45), patient age and number of children (r = .32), months since diagnosis and chemotherapy (r = .30), cancer stage and radiation therapy (r = -.30), cancer stage and in current treatment (r = -.40), college education and working (r = .31), months in relationship and divorce (-.33), and cancer stage and radiation therapy (r = .36).The only correlation between independent variables and the MOS sexual subscale were statistically meaningful at the cutoff set were MOS Total and menopausal symptoms (r = .39), and of note is the dependent variable correlation patient RDAS total (r = -.29). Overall, when participants reported higher dyadic satisfaction, there were fewer

reported issues with sexual function. In addition, more menopausal symptoms were correlated with more problems with sexual function.

Research Questions 2: Hierarchical Regression Analysis

Question 2: Does lower dyadic satisfaction predict sexual dysfunction in younger women with BCA above and beyond sociodemographic and BCA variables?

A hierarchical regression analysis was conducted to determine the relative contributions of sociodemographic factors, BCA, and relational variables that predict sexual dysfunction. Variables entered into the regression model were informed by the literature, the biopsychosocial model, and correlation results. The independent variables were entered into the regression model in three steps: 1) sociodemographic variables, 2) BCA variables, and 3) relational variables. These are summarized in Table 5.

Although BCA stage and ethnicity have been in other studies related to sexual function, our sample did not have enough respondents indicate their BCA stage (n = 22) and the sample was primarily white (93%), so these variables were not included in the regression model. Also, research has shown a positive relationship between income and education, so only education was kept in the model (Day & Newburger, 2002; Seccombe, 2001). Most participants were highly educated, so this variable was dichotomized as having at least some college education verses none.

Independent variables were entered in three blocks so that sociodemographic variables could be controlled for, and BCA variables could next be accounted for in the model. These two groups of variables have received more attention in the BCA literature, but need to be separated so that the contribution of the sociodemographic and BCA variables can be determined. The R-

DAS was added in step three to determine if dyadic satisfaction determines sexual function in above and beyond the other independent variables.

The results of the hierarchical regression analysis is broken down by each model and summarized in Table 6. The results of the first model indicated that sociodemographic variables did not account for a significant amount of the variance in sexual dysfunction, $R^2 = .01$, $F(3, 65) = .28$, $p = .84$. The results of the second model indicated that sociodemographic and breast cancer variables did account for a significant amount of the variance in sexual dysfunction, $R^2 = .35$, $F(9, 59) = 3.59$, $p = .00$. The results of the third model indicated that sociodemographic, breast cancer, and relational variables accounted for a significant amount of the variance in sexual dysfunction, $R^2 = .44$, $F(10, 58) = 4.52$, $p = .00$. These results suggest that when entered with sociodemographic and BCA variables, dyadic satisfaction contributed to the model to predict sexual dysfunction among younger women with BCA.

CHAPTER 5

DISCUSSION

Sexual Function

Consistent with the literature, women in this study reported problems with sexual function, including specific problems related to interest, arousal, orgasm, and relaxing/enjoying sex. Other studies have shown that the frequency of sexual behaviors and level of arousal is lower than that of healthy samples (Arora et al., 2001; Barni & Mondin, 1997; Brandberg et al., 2003; Broeckel et al., 2002; Dow & Lafferty, 2000; Fobair et al., 2006; Ganz et al., 1998; Ganz et al., 1999; Kornblith et al., 2003; Lindley et al., 1998; Schover et al., 1994; Thors, Broeckel, & Jacobsen, 2001; Young-McCaughan, 1996). In this study, two thirds of participants indicated they had been sexually active in the past month. A cross-sectional study examining sexual activity of healthy women and women at-risk for BCA indicated approximately 94.1% of healthy women were sexually active (Thirlaway, Fallowfield, & Cuzick, 1996). BCA samples in the literature occasionally indicated sexual activity in the past month, and ranged from 65 - 85% (Burwell, Case, Kaelin, & Avis, 2006; Fobair et al., 2006; Ganz et al., 1998). As others have suggested, women may be more concerned about their survival than sexual activity at this particular juncture (Fobair et al., 2006; Takahashi & Kai, 2005; Thewes et al., 2004; Wenzel et al., 1999), so it is not surprising that two thirds of the women in this sample reported being sexually active.

Overall this study found nearly 50% of women reported sexual dysfunction in at least one domain, which is also consistent with the other study findings (Barni & Mondin, 1997; Burwell, Case, Kaelin, & Avis, 2006; Fobair et al., 2006; Ganz et al., 1998). One study using the MOS Sexual Problems Scale that found 52% of women reported a little bit of a problem in two or

more areas of sexual functioning and 28% reported a problem ranging from small to serious in one or more domains including interest (57%), arousal (48%), orgasm (36%), and ability to relax/enjoy sex (40%) (Fobair et al., 2006). Barni and Mondin (1997) report slightly lower levels of sexual dysfunction in related domains including desire (48%), dyspareunia (38%), frigidity (42%), and female orgasmic disorder (30%). The DSM-IV TR is helpful in discussing these domains of sexual dysfunction.

Within this sample, women reported problems with interest (65%), arousal (58%), orgasm (44%), and relaxing/enjoying sex (47%). The DSM-IV TR classifies sexual dysfunction as problems related to sexual desire and psychophysiologic changes that interrupt the sexual response cycle (desire, excitement, orgasm, and resolution) (APA, 2000). A large proportion of women in this sample may be experiencing sexual dysfunction due to a general medical condition. Specifically, the women indicating problems with interest should be assessed for hypoactive sexual desire disorder, which addresses problems related to pain or lack of interest in sexual activity. The 58% of women experiencing problems with arousal should be assessed for arousal disorder, and the 44% experiencing problems with orgasm for orgasmic disorder. Also, for those women indicating problems with relaxing and enjoying sex, sexual pain disorders such as dyspareunia may be relevant. These results do not suggest that these women *have* a sexual dysfunction problem identified in the DSM-IV TR, but it does suggest that women should be assessed for the possibility of sexual dysfunction. This is consistent with the research that suggests that sexual dysfunction is prevalent among young women with BCA (Barni & Mondin, 1997; Burwell, Case, Kaelin, & Avis, 2006; Fobair et al., 2006; Ganz et al., 1998; Lindley et al., 1998). Doctors may want to make referrals for women in which these disorders may be present to health care professionals as highlighted in suggestions for medical family therapists.

The aims of this study focused on sociodemographic, BCA, and relational variables and their association with and prediction of sexual dysfunction. Although this study did not find any sociodemographic variables to be significantly associated with sexual dysfunction, other studies have found that younger patient age was associated with sexual dysfunction (Fobair et al., 2006; Ganz et al., 2003; Gould et al., 2006; Meyerowitz et al., 1983; Schover, 1994). Young women with BCA have more sexual dysfunction due to a variety of reasons such as higher likelihood of being depressed following diagnosis, more body issues, more functional impairment, more anxiety related to diagnosis and treatment, issues with fertility, more aggressive treatment, and negative partner response to BCA diagnosis (Al-Ghazal et al., 2000; Broeckel et al., 2002; Dow & Lafferty, 2000; Fobair et al., 2006; Ganz et al., 1998; Ganz et al., 1999; Ganz et al., 2003; Greendale et al., 2001; Schover et al., 1994; Thewes et al., 2004; Walsh, Manuel, & Avis, 2005; Wolberg et al., 1987; Young-McCaughan, 1996; Yurek, Farrar, & Andersen, 2000). In a study assessing health-related quality of life, young women with BCA had more sexual dysfunction than older BCA patients (Ganz et al., 1998). These studies defined younger and older ages to be above or below 50 years old, as consistent with the American Cancer Society definition of younger women with BCA (American Cancer Society, 2008). This study used this age guideline as well.

Other studies have found different results related to sexual function (Wenzel et al., 1999; Wimberly et al., 2005). In a study on age-related quality of life, younger women did not report significant changes in sexual functioning due to age (Wenzel et al., 1999). Another cross-sectional study on psychosexual adjustment by Wimberly and colleagues found age was negatively related to sexual functioning. Overall, age range does seem to be a factor in sexual dysfunction due to more aggressive treatment regimens reported in the literature although this

study did not support these findings (Wenzel et al., 1999; Wimberly et al., 2005). Literature related to age and sexual function contains mixed conclusions and more research is needed to explain this relationship.

When adding BCA and relational variables in the third model, having college education became a significant predictor. This suggests a possible interaction effect between the variables. However, in a national sample of 1,749 healthy women aged 18-59 years assessing sexual dysfunction, attending college was positively correlated with better sexual functioning (Laumann, Paik, & Rosen, 1999). The results in this study are probably inconsistent because the distribution of education was skewed. Most of the sample had at least some college education (88%), which is not representative of the population. Therefore, inferences about why this variable was a significant predictor were not made.

Menopausal symptoms were a predictor of sexual dysfunction indicating that women reporting more menopausal symptoms reported more sexual dysfunction. This finding is consistent with the literature that shows that younger women, who receive aggressive treatments such as chemotherapy and radiation, can have menopause related side effects and can even put women into premature menopause (Berglund et al., 2001; Rogers & Kristjanson, 2002; Winer et al., 1999; Young-McCaughan, 1996). In a study by Young-McCaughan (1996), BCA patients completed a two-part questionnaire concerning menopausal symptoms and sexual functioning. Women treated with chemotherapy reported more hot flashes and vaginal dryness than those women not treated with chemotherapy. These women also reported more sexual problems including decreased desire, more dyspareunia, and difficulty in achieving orgasm. Hormone therapy did not alter the results. Other studies reported similar findings (Berglund et al., 2001; Brandberg et al., 2003; Rogers & Kristjanson, 2002; Winer et al., 1999). In this study,

menopausal symptoms included pain with sex and vaginal dryness, which may be particularly influential in problems with sexual desire, arousal, orgasmic, and pain disorders.

While menopausal symptoms influence physical changes in women with BCA that make sexual activity difficult, it also can impact women psychologically. A qualitative study by Wilmoth (2001) describes 18 women aged 35-68 with BCA and their feelings about their sexual selves after lumpectomy or mastectomy. One theme that emerged was how traumatic the existence of menopausal symptoms became for these young women. Women said that when they had not anticipated menopausal symptoms brought on by chemotherapy, they felt a loss of womanhood. They also reported these symptoms were distressing, and often resulted in vaginal dryness or more pain with sex that negatively impacted sexual function. This finding is supported in other studies (Anllo, 2000; Barni & Mondin, 1999; Fobair et al., 2006; Ganz et al., 1998; Greendale et al., 2001; Meyerowitz et al., 1999; Schover, 1994; Thors, Broeckel, & Jacobsen, 2001; Young-McCaughan, 1996). Despite these sexual problems, most women found their partner helped them cope with these problems and did not experience relationship problems or less relationship satisfaction as a result (Barni & Mondin, 1999; Burwell, Manuel, & Avis, 2005; Ganz et al., 1999; Kershaw et al., 2004; Wilmoth, 2001).

In addition, women experiencing sexual dysfunction may be having more symptoms of sexual desire or arousal disorder due to more psychological than physiological symptoms as supported by breast reconstruction accounting for a significant proportion of the variance in sexual dysfunction. Many of the women in the sample underwent mastectomy and reconstruction, which carries with it some of the psychological and emotional barriers to sexual function described above. In addition, because our sample of women were on average diagnosed within a year when taking the survey, women undergoing breast reconstruction (40%) may still

be experiencing some of the short-term physiological pain that follows major surgeries of any type (Moyer, 1997).

In this study, the data indicated a negative association between dyadic satisfaction and sexual dysfunction such that the more dyadic satisfaction a patient reported, the higher they reported problems with sexual function. This contrasts much of the literature that indicates that BCA can put a strain on the sexual relationship between patient and partner such that it has an impact on dyadic satisfaction or vice versa (Anllo, 2000; Fobair et al., 2006; Ganz et al., 1996; Ganz et al., 1999; Kershaw et al., 2004; Meyerowitz et al., 1999; Schover, 1991; Schover, 1994; Speer et al., 2006; Takahashi & Kai, 2005; Thewes et al., 2004; Walsh, Manuel, & Avis, 2005; Wimberly et al., 2005). In one cross-sectional study, patients who perceived their partners as emotionally involved in the relationship had more positive psychosexual adjustment (Wimberly et al., 2005). One difference here is that many of the studies identified more specific aspects of dyadic satisfaction and adjustment such as level of distress, coping, partner's understanding of the patient's feelings, and partner response to BCA diagnosis and treatment, whereas the present study uses a sum score to explain dyadic satisfaction. Some of the more specific aspects of dyadic satisfaction are highlighted in the literature.

Wilmoth's qualitative study mentioned above (2001) may help to understand the inverse relationship between relationship satisfaction and sexual function found in the present study. Overall, women in this study were experiencing sexual dysfunction, but also reported dyadic satisfaction. It may be that women in this study had partners who were positive in their response and supportive toward them, helping them cope with the sexual problems rather than withdrawing, avoiding, or using some other negative response. Similar themes were stated in a qualitative study by Holbert, Scott, William, and Fife (2001) addressing relationship issues of 10

women and with BCA and 5 partners. Women reported that issues with body image and perceived partner response to diagnosis and treatment were the most significant factors in sexual dysfunction that occurred. This is also described in Templeton and Burwell's (2008) research describing perceived partner response profiles among young women with BCA and found that partner responses predicting sexual dysfunction were unsupportive. In addition, patients reported inhibiting sexual activity out of fear of negative partner response to their body.

When partners had a negative impact on the patient, it sometimes pertained to communication about BCA (Abend & Williamson, 2002; Burwell, Manuel, & Avis, 2005; Fleming & Kleinbart, 2001; Kershaw et al., 2004; Fobair et al., 2006). In Fobair and colleagues' (2006) cross-sectional study of 549 women, body image and sexual problems were assessed in young women with BCA, and patients reported more sexual problems when one's partner had difficulty understanding one's feelings in general. When asked in another study about communication specific to cancer, patients revealed similar findings (Abend & Williamson, 2002; Fleming & Kleinbart, 2001; Kershaw et al., 2004; Walsh, Manuel, & Avis, 2005). Communication may be an integral piece to understanding dyadic variables significant in contributing to sexual problems. These specific factors related to patient and partner relationship only begin to explain the complexity of relationships. More research is needed with communication and partner response to cancer to determine more specific direct or moderating effects of the relationship on sexual dysfunction.

If relationship satisfaction had a moderating effect between sexual dysfunction and psychological functioning, it may helpful to explore its buffering effects. In the Wilmoth study, women stated that even though their partners were supportive (emotionally and instrumentally), there was a decrease in sexual activity due to bodily changes brought on by menopausal

symptoms, side effects of treatment such as fatigue or pain, and emotional distress. Many partners described actively trying to provide emotional and instrumental support to their partner to show concern. They also discovered that BCA variables such as cancer stage and symptom severity related more to sexual dysfunction than changes in the relationship. Although a couple women mentioned being unhappy in their relationship, most women indicated that even though they were experiencing treatment-related side effects such as fatigue, their partner was able to provide support and had a significant impact on their ability to deal with these physiological changes.

This study may also provide support for the notion that the dyadic relationship can grow closer as a result of BCA treatment (Walsh, Manuel, & Avis, 2005). In a study on the impact of BCA on young women's relationships with their partner and children, partner affection, interaction, and neglect were not reported as problems experienced by women with BCA. In fact, 75% of respondents reported their relationship with their partner became closer after being diagnosed with BCA, even though 68% reported problems related to sexuality such as feeling self-conscious and were affected side effects from treatment that led to problems such as pain with sexual intercourse and fatigue. Therefore, this study demonstrates that although partners may grow closer as a result of BCA diagnosis, sexual dysfunction can co-occur (Walsh, Manuel, & Avis, 2005).

However, in the study by Meyerowitz et al. (1999) and Greendale et al., (2001), the Dyadic Satisfaction Survey was administered, and women were more likely to report BCA had a negative impact on sexuality when reporting problems in their relationship. Speer et al. (2005) also measured dyadic satisfaction with the Marital Satisfaction Inventory-Revised and found that level of relationship distress was the most significant variable influencing arousal, orgasm,

lubrication, satisfaction, and sexual pain. Overall, relationship distress or lower dyadic satisfaction does seem to have a negative impact on sexual functioning in some of the literature (Abend & Williamson, 2002; Meyerowitz et al., 1999; Speer et al., 2005; Wimberly et al., 2005). The literature has established a link between relationship satisfaction and sexual function, but the conclusions are unclear and need more research.

A few studies also brought up the relative importance of sexual functioning after being diagnosed with BCA. Women brought up that after being diagnosed, sexual activity may have decreased, but was not their largest concern. Concerns were related more to fear of death, anxiety about treatment, and so forth (Holbert et al., 2001). Two other cross-sectional studies indicated that over half of the women in their sample were not sexually active because they did not feel having sex was an important part of life (Fobair et al., 2006; Meyerowitz et al., 1999).

Another explanation for sexual dysfunction may be related to women feeling a loss of femininity following BCA surgery (Andersen & Jochimsen, 1985; Fobair et al., 2006; Lund-Neilsen, Muller, & Adamsen, 2005; Takahashi & Kai, 2005; Wilmoth, 2001). Some women even avoided sexual activities for fear that their wound or scar would make their partners anxious (Takashasi & Kai, 2005). In one study, women suppressed their need for sexual activity because of their surgical wounds that made them anxious about how the wound might smell or look to others and did not feel comfortable engaging in sexual activity or physical closeness. In this case, patients still had interest in engaging in sexual activity, but did not feel comfortable doing so. However, after patients were given psychoeducational and support resources for wound care, they reported desire to engage in sexual activity again (Lund-Nielsen, Muller, & Adamsen, 2005). Given these findings, it may be that the women in this study have high dyadic satisfaction, but feelings of self-consciousness, loss of femininity and/or sexual attractiveness

may have increased problems with interest and arousal (Andersen & Jochimsen, 1985; Taylor, Lamdan, Siegel, Shelby, Hrywna, & Klimi, 2002; Wilmoth, 2001).

In addition, psychological functioning has been shown to have an impact on sexual functioning and younger age has been associated with more depressive and anxiety symptoms in BCA patients in the literature (Fobair et al., 2006; Takahashi & Kai, 2005; Thewes et al., 2004; Wenzel et al., 1999). In the qualitative study by Takahashi and Kai (2005) where they interview 21 Japanese women about sexuality after breast cancer treatment, women reported an absence of sexual interest due to these symptoms of depression and anxiety instead of dyadic satisfaction. In another qualitative study by Thewes and colleagues (2004), patients reported similar results, and said that pain with treatment and fear of the possible progression or recurrence of the disease overshadowed her need for a "sex life." Taken together, sexual dysfunction may be impacted more by psychological functioning than dyadic satisfaction.

In explaining why women experienced sexual dysfunction, the picture is not clear. There are BCA, sociodemographic, partner, and psychological variables at play. This study was able to show that these components often work together to contribute to sexual health or dysfunction. More studies are needed to tease apart the strength and direction of these effects.

Implications for Medical Family Therapists

Medical Family Therapy (MedFT) is an approach that evolved from Engel's (1977) biopsychosocial model and emphasizes collaboration between health care professionals and agency and communion with patients with medical issues such as BCA (McDaniel, Hepworth, & Doherty, 1992). Agency refers to commitment and involvement with one's illness. Communion is the support needed by family, friends, and the health care system in coping with an illness. Oftentimes BCA can give patients a sense of loss of control over their bodies, but MedFT's can

help patients to find agency in decision making pertaining to BCA and in maintaining or building a strong relationship with one's partner (McDaniel, Hepworth, & Doherty, 1992).

Psychoeducation is important in helping patients feel a sense of agency in dealing with BCA. In several studies, women reported wishing they had more knowledge pertaining to how treatment options and surgery types may have an affect on sexual function. With knowledge of what breast cancer is, treatment options, and how they may have an affect on sexuality or relationships, patients may have more knowledge to make decisions pertaining to treatment and recovery (Burwell et al., 2008; Gould et al., 2006). MedFTs can help give patient's agency by encouraging them to speak to their doctor about concerns related to sexual dysfunction.

In general, couples and sex therapy can be helpful in exploring emotional and relational strains in a relationship. Sex therapists will have specialized knowledge and experience with helping couples deal with sexual desire, arousal, orgasmic, and pain disorders due to BCA. Literature has shown that although some couples grow closer after breast cancer diagnosis, some do not (Walsh, Manuel, & Avis, 2005). In addition, couples who may not evidence problems with relationship satisfaction may still find sex therapy helpful in discussing issues related loss of femininity, fear of rejection, unexpected physiological side effects of treatments, and so forth. Sex therapists can help address some physiological problems by talking about vaginal lubricants and moisterizers, wearing a prosthesis, systematic desensitization (with touching the surgical scar), choosing clothing after mastectomy, and so forth (Fleming & Kleinbart, 2001; Meyerowitz et al., 1999). It is necessary to remember that dyadic satisfaction can play a role in predicting sexual function.

In addition, MedFTs should address communication patterns in couples dealing with a patient's BCA diagnosis (Walsh, Manuel, & Avis, 2005; McDaniel, Hepworth, & Doherty, 1992). In one cross-sectional study of 50 women in an outpatient clinic, women indicated that they found their partner the easiest person to discuss sexual problems with during their illness (Barni & Mondin, 1997). This gives support to how integral partners are in patient's coping with sexual problems. If healthy communication patterns are not established, the patient may not feel comfortable sharing fears or anxieties related to breast cancer diagnosis, treatment, and its affect on sexual function. As the literature suggested, many patients do not feel understood and find it difficult to talk about BCA with their partner. MedFTs can help facilitate open discussion about some of these issues and elicit some of the patient's needs.

Specific topics pertaining to young women include concerns with body image, fertility, menopausal symptoms, and pregnancy. Each of these may have been disrupted as a result of breast cancer, and are not necessarily short term. One study by Kornblith and colleagues (2003) reported that 29% of 20 year survivors of breast cancer reported having sexual problems due to adjuvant chemotherapy treatment. Alterations of the life cycle can disrupt timing of pregnancy, parenthood, roles in the family, and personal independence (Rolland, 1999). It may be helpful for BCA patients to talk through some of these unexpected changes and how to negotiate them (McDaniel, Hepworth, & Doherty, 1992; Rolland, 1999).

In addition, MedFTs should try to increase communion for the patient. Patients may be dealing with issues such as problems with sexual function that they do not want to share with others, and may feel socially isolated in experiencing problems related to BCA (Lund-Nielsen, Muller, & Adamsen, 2005). Therapists can help by incorporating the partner into therapy. In addition, a MedFT can talk with the patient to help build her support system or recommend a

BCA support group if one is available. Support groups can offer women communion, especially when groups are offered for young women in order to find women dealing with the same issues they are and to find understanding, support, and validation.

Limitations

Several limitations should be discussed when interpreting the results. First, this study is cross-sectional and does not measure change in sexual function over time. Cross-sectional studies may not have as much support in claiming causation as longitudinal studies may. In this study, patients may have participated before, during, or after treatment. As this study suggests, BCA variables can be significant predictors of sexual dysfunction and future studies should try and assess patients before and after treatment for a more accurate measure of change.

Also, this sample is fairly homogeneous and is relatively small. As indicated in the demographic characteristics, most participants were white, well educated, and middle to upper class. In spite of non-Hispanic white women tending to have higher rates of BCA than any other ethnic or racial background, African American women and Hispanic women tend to have lower survival rates, are diagnosed at a later stage, have longer time periods between diagnosis and treatment completion, and may receive more aggressive treatment as a result of diagnosis at later stages (Lannin, Mathews, Mitchell, Swanson, Swanson, & Edwards, 1998; Li, Malone, & Daling, 2003; Press, Carrasquillo, Sciacca, & Giardina, 2008). Therefore, African American and Hispanic women may experience more aggressive cancer treatments that may result in more menopausal symptoms and sexual side effects (Taylor et al., 2002). Some researchers have hypothesized that this disparity may also occur due to socioeconomic status, which is correlated with education level (Lannin et al., 1998; Li, Malone, & Daling, 2003; Rowan-Kenyon, Bell, & Perna, 2008). More research is needed with diverse samples.

In regard to our understanding of "sexually active," future studies should either define this construct or ask patients what their definition of “sexually active” is. For instance, some women may perceive being sexually active as sexual intercourse whereas others may perceive it as sexual touching. In this survey women were asked women whether or not they were sexually active (yes/no) so we are unable to determine participant’s specific definition of what sexually active meant for them.

Marital and partner relationships are also important in studying sexual function in young women (Burwell et al., 2008; Northouse, Kershaw, Mood, & Schafenacker, 2005; Northouse, Templin, & Mood, 2001; Takahashi & Kai, 2005; Thewes, Butow, Girgis, & Pendlebury, 2004; Walsh, Manuel, & Avis, 2005; Wimberly et al., 2005) and partner data was not included in this study. Although some partner data was obtained in the larger study, few partners actually participated despite major recruitment efforts. Some studies that include partner data recruited men at large medical hospitals, which were not available for this study (Kershaw et al., 2004; Wimberly et al., 2005). Anecdotally, some men have reported that their partner’s BCA was too hard to talk about, or they did not want to talk about it more than they needed to outside of the family. Future studies should explore this and include partner data into their study to give a fuller picture of sexual dysfunction.

Most of the women in this study indicated that they were not relationally distressed (66%) according to the R-DAS. Because two thirds of patients were not relationally distressed, it is difficult to tease apart the influence of relational distress on sexual function. More specific domains of relationship distress such as communication, satisfaction, and partner’s response to cancer may also be helpful.

In terms of recruitment, the majority of participants (96%) in this study were recruited online. Although online sampling provided opportunities to reach a large amount of potential participants, one study evaluating online sampling suggests there may be issues with validity and missing data (Cantrell & Lupinacci, 2007). In this sample, many participants had to be removed because of incomplete data or not meeting eligibility criteria, even though the criteria were made explicit. In some cases, women completed portions of the survey, but chose not to answer the questions about sexual function. These participants may not be as comfortable sharing information about their sexuality. Because of the anonymous nature of online surveying, participants who chose not to leave their contact information could not be contacted about the missing items (Cantrell & Lupinacci, 2007). Other research pertaining to online surveying has compared online surveying to offline surveying in the field of psychology. Researchers have shown similar test-retest reliability statistics with online surveying and paper surveying, but remark that this has only been done with previously validated measures (Buchanan & Smith, 1999; Miller, Neal, Roberts, Baer, Cressler, Metrik, & Marlatt, 2002; Riva, Teruzzi, & Anolli, 2003). In a cross-sectional study by Riva, Teruzzi, and Anolli (2003), undergraduate students were recruited at a large university by flyers to take a survey online concerning demographic variables, computer usage, and attitudes about the internet. Paper surveys were administered in undergraduate classes at the university. Even though the researchers could not control the characteristics of the sample online, findings and consistency of responses from the paper verses online surveying did not differ significantly. Therefore, online sampling and surveying has potential benefits, but control of participant characteristics may be difficult (Cantrell & Lupinacci, 2007; Riva, Teruzzi, & Anolli, 2003).

Conclusion

This study used the biopsychosocial model to examine sexual dysfunction in BCA patients. Some of the proportion of variance accounted for in sexual dysfunction was explained by the model including sociodemographic, BCA, *and* relational variables. Medical family therapy may be a useful resource to help women with sexual dysfunction following BCA diagnosis and in the development of specific interventions that target predictors of sexual dysfunction, particularly marital or relational dissatisfaction. More research is needed to determine exactly what aspect(s) of the marital or couple relationship hinders sexual function.

Table 1

Dichotomized Independent Variables

Variable Name	***Value***
Education	1 = at least some college education 0 = less than some college education
Ethnicity	1 = White 0 = Non-white
Work Status	1 = working part or full time 0 = not working
Income	1 = $10,000 - $39,000 $40,000 - $59,999 $60,000 - $74,999 $75,000 and above 0 = not in the category
Marital Status	1 = Married 0 = Not married
Divorce History	1 = Previous divorce 0 = No history of divorce
Children	1 = yes 0 = no
Treatment types (e.g., chemotherapy)	1 = yes 0 = no
Surgery types (e.g., mastectomy)	1 = yes 0 = no
In current treatment	1 = yes 0 = no
Health Insurance	1 = yes 0 = no
Current Health Perception	1 = fair to excellent 0 = poor

Table 2

Participant Characteristics (N = 106)

Variables	*N% or Mean*	*SD*
Patient age	40.58	7.02
Partner age	42.42	7.85
Relationship Status		
Married	84.2%	
Partnered	15.8%	
Missing	4.7%	
Length of relationship (months)	154.21	102.71
Number of times married	1.19	.66
Number of times divorced	.35	.57
Ethnicity		
White	93.2%	
Non-White	2.9%	
Missing	2.8%	
Education		
High school graduate or GED	11.7%	
Some college/Associate's degree	30.1%	
College graduate	25.2%	
Above college graduate	33.1%	
Missing	2.8%	
Work status		
Full time	44.7%	
Part time	22.3%	
Stopped working due to health	10.7%	
Not working	5.7%	
Missing	2.8%	
Income		
$10,000 - $39,999	6.8%	
$40,000 - $59,999	18.4%	
$60,000 - $74,999	15.5%	
$75,000 or above	59.2%	
Missing	2.8%	

Have children	79.0%	
Months since diagnosis	11.84	9.61
Adjuvant treatment		
Chemotherapy	75.5%	
Radiation therapy	62.9%	
Hormone therapy	57.4%	
Other treatment	41.6%	
Type of surgical treatment		
Mastectomy	54.7%	
Lumpectomy	71.9%	
Reconstruction	39.8%	
Auxillary node dissection	81.5%	
Currently in treatment	73.1%	
Menopausal Symptoms Severity*	12.12	4.36
Cancer stage		.89
I	33.3%	
II	38.1%	
III	23.8%	
IV	4.8%	
Missing	80.2%	
Patients with health insurance	99.0%	
R-DAS		
Distressed	34.0%	
Non-Distressed	66.0%	
Missing	2.8%	
Sexually active during the past month	68.6%	

*Sum score: Higher scores indicate higher symptom severity (6-30)

Table 3

Descriptive Statistics for Medical Outcomes Study Scale

Variable	Percentage
MOS Total Score	
0-25	29.2%
26-50	29.2%
51-75	12.3%
76-100	29.2%
MOS by Domain	
Problem with Interest	65.1%
Problem with Arousal	57.5%
Problem with Orgasm	44.3%
Problem with Relax/Enjoy sex	47.1%

Higher scores indicate better sexual function
Domain broken down by "problem" (strongly agree or agree) or "not a problem" (neutral, disagree, or strongly disagree)

Table 4

Correlations of Independent and Dependent Variables (N = 106)

Variables	1	2	3	4	5	6	7	8	9	10	11
1. MOS Total Score	–										
2. Education[a]	.03	–									
3. Patient age	.01	-.07	–								
4. Months in relationship	.09	-.14	.62*	–							
5. Menopausal Symptoms	.39*	-.15	.00	.01	–						
6. In Current Treatment	.02	-.13	.06	.06	-.08	–					
7. Chemotherapy	-.14	.10	.16	.01	-.25*	.09	–				
8. Radiation	-.17	.18	-.20	-.27*	-.10	.00	.27*	–			
9. Mastectomy	-.10	.12	-.02	-.15	0.12	.07	.28*	-.01	–		
10. Reconstruction	.04	-.01	.02	-.09	-.10	-.01	.15	-.19	.82*	_	
11. Dyadic Satisfaction	.29*	.14	-.01	-.01	-.08	.03	.04	.12	-.07	-.06	_

[a]0 = less than college education, 1 = at least some college

*$p < .05$

Table 5

Hierarchical Regression Model: Order of Entry

Step	**Independent Variables**
1	Sociodemographic: patient age, months in relationship, education (1 = at least some college; 0 = not in college)
2	BCA: Menopausal symptoms, in current treatment, chemotherapy, radiation therapy, mastectomy, breast reconstruction
3	Relational: RDAS total

Table 6

Summary of Hierarchical Regression Analysis for Variables Predicting Sexual Dysfunction (N = 106)

	Model 1		Model 2		Model 3	
Variable	*B*	*SE B*	*B*	*SE B*	*B*	*SE B*
Education	7.70	12.72	22.10	11.38	30.60	11.09
Months in Relationship	.04	.05	.04	.05	.03	.04
Patient age	-.33	.75	-.57	.67	-.39	.63
Menopausal Symptoms			4.15	.85	4.20	.80
Mastectomy			-31.92	11.90	-37.43	11.35
Chemotherapy			8.37	8.17	6.51	7.71
Radiation			-.46	7.40	-3.22	6.98
In Current Treatment			2.24	8.13	5.89	7.75
Breast Reconstruction			35.61	12.50	41.08	11.91
Relationship Satisfaction					-.96	.33
R^2		.01		.35		.44
F for change in R^2		.28		3.59**		4.52**

*$p < .05$. **$p < .01$.

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Appendix A: Cover Letter and Informed Consent

Couples Coping with Breast Cancer
Patient Survey

Principal Investigator: Dr. Stephanie Burwell

BASELINE
SELF ADMINISTERED QUESTIONNAIRE

Date: | | | | | **2006**

MONTH **DAY**

CONFIDENTIAL

Thank you for completing this survey. It should take no more than 30 minutes. For most questions, you will be asked to circle your answer. On some questions, you will be asked to write out your answer.

There is no right or wrong answer. Please answer each question as accurately as you can. It is important to the project goals that all information be as complete as possible. Your opinions are important to us, so please let us know what you think.

If you have any questions, please call Dr. Stephanie Burwell at (706) 542-4897. We appreciate your help with this important research.

Informed Consent

Dear Breast Cancer Survivor:

I am Dr. Stephanie Burwell in the Department of Child and Family Development at The University of Georgia. I invite you to participate in a research study entitled "The Psychosocial Needs of Women Aged 50 and Younger with Breast Cancer and their Partners".

The purpose of this study is to learn about the psychosocial needs of younger women with breast cancer and those of their spouse or partner.

Please do not participate if you are not 18 years old or over.

If you agree to be in this study, you will complete a web-based survey that asks about your experiences related to coping with breast cancer. It should take approximately 45 minutes to complete. You can skip any questions that you do not wish to answer. As you complete the survey, your answers can be sent over the Internet by clicking on the NEXT button at the end of each page. If you do not wish to submit a response, please do not respond to the question. If you do not click NEXT, your responses will not be recorded or submitted to the researchers. In addition, with your permission, we may contact you 2-3 weeks after you participate to seek clarification or more information regarding your responses.

Please note that Internet communications can be insecure. We cannot guarantee your privacy and confidentiality while the data is transmitted to us over the Internet. However, once we receive the completed surveys, any information that is obtained in connection with this study and that can be identified with you will remain confidential except as required by law. All records pertaining to your participation will be kept in a password protected computer. When all of the data have been collected and analyzed, any individually identifying information pertaining to you will be removed or changed from our research records. If you are not comfortable with the level of confidentiality provided by the Internet, please feel free to print out a copy of the survey, fill it out by hand, and mail it to me at the address given below, with no return address on the envelope.

There are no direct benefits to you but the findings from this project may provide information on the psychosocial needs of younger women with breast cancer and their spouse or partner so that resources targeting these needs may be developed.

There are some minimal risks or discomforts associated with this research. They include psychological discomfort as you think about breast cancer and how it has affected you and your relationship with your spouse or partner. The risk of harm or discomfort that may happen as a result of taking part in this research study is not expected to be more than in daily life or from routine psychological examinations or tests.

As compensation, you will be entered into a raffle for a $60 gift card to Wal-mart. Your participation is voluntary. Your may refuse to participate or discontinue participation at any time

without penalty or loss of benefits to which you are otherwise entitled.

The researcher can be contacted for any further questions about the research, now or during the course of the project. Please see contact information for the researcher at the bottom of the page. Additional questions regarding your rights as a research participant or in the event of a research related injury should be addressed to The IRB Chairperson, University of Georgia, 612 Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411; Telephone (706) 542-3199; E-Mail Address: IRB@uga.edu

By clicking on the link below, you are agreeing to participate in the above described research project.

Thank you for your consideration and important participation! Please keep this letter for your records.

Sincerely,

Dr. Stephanie Burwell
The University of Georgia
Department of Child and Family Development
123 Dawson Hall
Athens, GA 30602-2622
Phone: (706) 542-4897
Email: sburwell@uga.edu

I agree to take part in this study. My signature below will be indicated by checking the "I agree" box that the researchers have answered all of my questions to my satisfaction and that I consent to volunteer for this study.

□ I agree

□ I do not agree

Appendix B: Background Information

1.a **PATIENT** Date of Birth: _____ **PARTNER** Date of Birth: _____

Age: _____ Age: _____

1.b Gender: ☐ Female ☐ Male

1.c Marital Status: ☐ Married ☐ Not Married

1.d Length of relationship or marriage: (years/months) _____

1.e Does your spouse or partner live with you? Yes_____ No_____

---

2. Number of times you have been married:

0 ____ 2 ____ 4 ____

1 ____ 3 ____ 5 or more ____

---

3. Number of times you have been divorced:

0 ____ 2 ____ 4 _____

1 ____ 3 ____ 5 or more _____

---

4. Number of times you have been widowed:

0 ____ 2 ____ 4 ____

1 ____ 3 ____ 5 or more ____

5.a Do you have children? ☐ Yes ☐ No

5.b Please list the age(s) of your child(ren):

Females:

Males:

---

6. Approximate yearly income before taxes of self and partner combined:
   - ☐ less than $10,000
   - ☐ $10,000 - $19,999
   - ☐ $20,000 - $39,999
   - ☐ $40,000 - $59,999
   - ☐ $60,000 - $74,999
   - ☐ $75,000 or above

7. What is the highest grade or year of school you have completed?

   - ☐ No formal education
   - ☐ Grade School (1-8 years)
   - ☐ Some High School (9-11 years)
   - ☐ High School graduate or equivalency (12 years or GED)
   - ☐ Vocational or Training School after High School Graduation
   - ☐ Some College
   - ☐ Associate Degree
   - ☐ College Graduate
   - ☐ Some College or Professional School after College Graduation
   - ☐ Completed a Master's Degree
   - ☐ Completed a Doctoral Degree (PhD, MD, DDS, JD, etc.)

8. How would you describe your racial or ethnic group? If you are of mixed blood, which group do you identify with most?

   - ☐ White (not of Hispanic origin)
   - ☐ Black or African-American (not of Hispanic origin)
   - ☐ Hispanic/Latino (ancestry is Mexican, Cuban, Puerto Rican, Central American, or South American)
   - ☐ American Indian or Alaskan Native
   - ☐ Asian or Pacific Islander (ancestry is Chinese, Indo-Chinese, Korean, Japanese, Pacific Islander, Vietnamese)
   - ☐ Other (please specify):_____

9. Which of the following best describes your work status?

- ☐ Working full-time (35 hours or more)
- ☐ Working part-time (less than 35 hours)
- ☐ Stopped working due to ill health
- ☐ Retired
- ☐ Was never in paid employment
- ☐ Unemployed or searching for work
- ☐ Student
- ☐ Other, please specify: _____

Do you have health insurance?

a. Yes
b. No

Is your spouse or partner covered on your health insurance?

c. Yes
d. No

Appendix C: Breast Cancer History

A.1 When was your breast cancer first diagnosed? ☐☐ ☐☐☐☐
MONTH YEAR

A.2 Since the time of diagnosis have you had any of the following?
(please circle "yes" or "no" for each type of treatment).

A.2.a.	Lumpectomy or partial mastectomy (*removal of a lump, with or without a wedge of normal tissue around it)* If yes, when was this? _____	1. NO 2. YES
A.2.b.	Axillary node dissection *(removal of underarm lymph nodes)* If yes, when was this? _____	1. NO 2. YES
A.2.c.	Mastectomy *(complete removal of a breast)* If yes, when was this? _____	1. NO 2. YES
A.2.d.	Breast reconstruction If yes, when was this? _____	1. NO 2. YES
A.2.e.	Chemotherapy If yes, when was this? _____	1. NO 2. YES
A.2.f.	Radiation Therapy If yes, when was this? _____	1. NO 2. YES
A.2.g.	Hormone Therapy If yes, when was this? _____	1. NO 2. YES
A.2.h.	Other treatment Please specify _____	1. NO 2. YES

A.3. Have you developed any other type of cancer? 1. NO 2. YES
If yes, what type and when was this diagnosed?
_____

A.4. Have you had a recurrence of breast cancer? 1. NO 2. YES
If yes, when was this? _____

A.5. Are you currently undergoing any treatment for cancer? 1. NO 2. YES

If yes, please describe your treatment:

Appendix D: Symptoms

How much have you been bothered by any of the following problems during **the past 4 weeks?** **(Please circle one number on each line)**

In the past 4 weeks I have been bothered by……..	**Not at all**	**A little**	**Some what**	**Quite a bit**	**Very much**
1. Hot flashes	1	2	3	4	5
2. Nausea	1	2	3	4	5
3. Vomiting	1	2	3	4	5
4. Diarrhea	1	2	3	4	5
5. Difficulty with bladder control when laughing or crying	1	2	3	4	5
6. Difficulty with bladder control at other times	1	2	3	4	5
7. Vaginal discharge	1	2	3	4	5
8. Vaginal dryness	1	2	3	4	5
9. Pain with sexual intercourse	1	2	3	4	5
10. General aches and pains	1	2	3	4	5
11. Swelling of hands and feet	1	2	3	4	5
12. Weight gain	1	2	3	4	5
13. Weight loss	1	2	3	4	5
14. Unhappiness with the appearance of your body	1	2	3	4	5

Appendix E: Health Status

Below are some questions about your current health status.

Compared to before you had cancer, how would you rate your health in general now? **(Circle one number.)**

1. Much better now than before cancer
2. Somewhat better now than before cancer
3. About the same
4. Somewhat worse now than before cancer
5. Much worse now than before cancer

Appendix F: Revised Dyadic Adjustment Scale

Most people have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

	Always Agree	**Almost Always Agree**	**Occasionally Agree**	**Frequently Disagree**	**Almost Always Disagree**	**Always Disagree**
1. Religious matters	☐	☐	☐	☐	☐	☐
2. Demonstrations of affection	☐	☐	☐	☐	☐	☐
3. Making major decisions	☐	☐	☐	☐	☐	☐
4. Sex relations	☐	☐	☐	☐	☐	☐
5. Conventionality (Correct or proper behavior)	☐	☐	☐	☐	☐	☐
6. Career decisions	☐	☐	☐	☐	☐	☐

	All the Time	**Most of the Time**	**More Often than Not**	**Occasionally**	**Rarely**	**Never**
7. How often do you discuss or have you considered divorce, separation, or terminating your relationship?	☐	☐	☐	☐	☐	☐
8. How often do you and your partner quarrel?	☐	☐	☐	☐	☐	☐

9. Do you ever regret that you married (or lived together?)	☐	☐	☐	☐	☐	☐
10. How often do you and your mate "get on each other's nerves"?	☐	☐	☐	☐	☐	☐

	Every Day	**Almost Every Day**	**Occasionally**	**Rarely**	**Never**
11. Do you and your partner engage in outside interests together?	☐	☐	☐	☐	☐

How often would you say the following events occur between you and your partner?

	Never	**Less than Once a Month**	**Once or Twice a Month**	**Once or Twice a Week**	**Once a Day**	**More Often**
12. Have a stimulating exchange of ideas	☐	☐	☐	☐	☐	☐
13. Work together on a project	☐	☐	☐	☐	☐	☐
14. Calmly discuss something	☐	☐	☐	☐	☐	☐

Appendix G: Medical Outcomes Study Sexual Problems Scale

SEXUAL FUNCTION

These next questions are about the way health problems may interfere with your sex life. These questions are personal, but your answers are important in understanding how health problems may affect your sexuality.

1. Have you been sexually active in the past month?

1. NO
2. YES

For the following questions, **please check the box for the response that best describes** your sexual feelings and experiences **during the past month.**

	Strongly Agree	**Agree**	**Neither Agree or Disagree**	**Strongly Disagree**	**Disagree**
1.a. Lack of sexual interest	1	2	3	4	5
1.b. Difficulty in becoming sexually aroused	1	2	3	4	5
1.c. Unable to relax and enjoy sex	1	2	3	4	5
1.d. Difficulty in having an orgasm	1	2	3	4	5
1.e. Partner lacking sexual interest	1	2	3	4	5