Lindsey A. Rosman, BODY IMAGE AND SEXUAL FUNCTIONING IN BREAST CANCER SURVIVORS (Under the direction of Dr. Heather Littleton) Department of Psychology, February 2013.

Background: For breast cancer survivors, sexual problems are one of the most common and distressing sequelae of cancer and its treatment. However, sexual problems are often undiagnosed and untreated. One potentially important, but understudied, risk factor for poor sexual adjustment after breast cancer is body image concern. For example, physical changes in appearance as a result of cancer treatment may alter how women perceive themselves and their bodies which may in turn increase risk for sexual problems. Therefore, the current study was designed to evaluate whether body image predicted sexual dysfunction and sexual dissatisfaction following breast cancer. In addition, mediation analyses evaluated body image as a mediator of the relationship between number of cancer-related changes in appearance and sexual dissatisfaction and sexual dysfunction. Mediation analyses also examined body image concerns during sexual activity as a mediator of the relationship between body image concerns and sexual dissatisfaction and dysfunction.

Methods: A sample of 219 U.S. breast cancer survivors was recruited via breast cancer websites, blogs, and social media websites to complete an online self-report survey about body image and sexual functioning after diagnosis and treatment for breast cancer.

Results: Participants' mean age was 47.3 years with an average time since diagnosis of 4.4 years. Women were predominantly European American, married, and diagnosed with Stage I or II breast cancer. On average, women in this sample experienced 6.1 (*SD* = 2.2) changes in their physical appearance due to cancer treatment, such as hair loss, breast disfigurement and changes to their skin. Sexual problems were common with 69% (*n* = 72) of sexually active survivors (*n* =

104) meeting criteria for sexual dysfunction. High levels of body image concerns were also reported. In regression analyses, medical treatment variables, general distress, and body image variables predicted sexual dissatisfaction, whereas only medical treatment variables and general distress predicted sexual dysfunction. Results from mediation analyses indicated that body image mediated the relationship between having a greater number of cancer-related changes in appearance and lower levels of post-treatment sexual dissatisfaction. Two of the body image variables also significantly mediated the relationship between experiencing a greater number of changes in appearance and post-treatment sexual dysfunction. Finally, higher levels of body image concern during sexual activity mediated the relationship between body image and sexual dysfunction as well as sexual dissatisfaction.

Conclusion: Overall, results suggest that body image concerns and sexual problems are prevalent and distressing for a majority of women diagnosed and treated for breast cancer. Many women also experience multiple changes in their physical appearance. In addition, body image concerns may be amplified in a sexual context due to the increased exposure of one's body during sexual activity. Implications for further research, routine assessment, and clinical management of these symptoms are discussed.

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CHAPTER I: LITERATURE REVIEW

There are more than 2 million breast cancer survivors currently living in the United States (American Cancer Society, 2008). With more widespread breast cancer screenings leading to earlier detection and advances in medical treatments, the majority of these women will live cancer-free for many years. However, the experience of having breast cancer and its treatment is associated with numerous physical, emotional and interpersonal disruptions including chronic pain, fatigue, financial debt, intimate partner relationship problems, depression and anxiety (Ganz, Desmond, Belin, Meyerowitz, & Rowland, 1999; Morrell et al., 2005). Many women face additional challenges related to changes in their physical appearance, such as difficulty coping with disfigurement due to treatment, fear of partner rejection, and body image concerns. Given the many physical and emotional changes associated with survivorship, it is not surprising that breast cancer can also affect survivors' sexual functioning and intimate relationships. Indeed, sexual problems are one of the most common consequences of breast cancer and its treatment, affecting an estimated 30 to 100% of survivors (Krychamn, Pereira, Carter, & Amsterdam, 2006). However, sexual problems are often undiagnosed and untreated, and may negatively affect women's emotional well-being and intimate partner relationships. Therefore, as survival rates continue to improve, quality of life issues, including sexual and intimacy concerns, have become increasingly important to breast cancer survivors and their loved ones.

Long-term Quality of Life Issues for Female Breast Cancer Survivors

For women diagnosed with early-stage invasive breast cancer, medical management of the disease typically involves a combination of surgical and chemical interventions designed to remove and destroy malignant tissue in the body. As a result, survivors often experience a prolonged physical recovery with symptoms that can persist for years after treatment. Among

breast cancer survivors, reduced physical health, chronic pain, fatigue and numbness in the arm, chest wall, or underarm are common (Bower et al., 2000; Carver et al., 2005; Ganz et al, 1999; Ganz et al., 2002). Other late and long-term side-effects of cancer and its treatment include vaginal dryness, weight gain, and cognitive impairment (Ganz et al., 2002). More recently, longitudinal research has documented particularly poor health outcomes among the 8 to 56% of breast cancer survivors who develop lymphedema, or swelling caused by fluid retention in the upper extremities (Morrell et al., 2005; Paskett, Naughton, McCoy, Case, & Abbott, 2007). Indeed, research has supported that as long as twenty years post-treatment, 39% of breast cancer survivors continue to experience functional limitations related to lymphedema, such as reduced strength, restricted mobility, and loss of dexterity (Kornblith et al., 2003; Morrell et al., 2005).

In addition to the physical impact of cancer and its treatment, many survivors experience significant psychological distress. Three years after initial treatment, 50% of breast cancer survivors report frequently feeling depressed (Ganz et al., 1996). Anger and anxiety related to their experience with cancer are also common, affecting 36% and 51% of breast cancer survivors respectively (Ganz et al., 1996). In particular, women report significant concerns about their overall health, concern about their children's future health, fear of cancer recurrence, and concerns about their family's ability to cope with recurrence (Deimling, Bowman, Sterns, Wagner, & Kahana, 2006; Ganz et al., 1996). Numerous studies have also documented high rates of cancer-related post-traumatic stress symptomatology in breast cancer patients. Indeed, in a study of survivors 20 years after treatment, 18% reported two or more cancer-related symptoms of PTSD, and 4.6% met criteria for a current diagnosis of cancer-related PTSD (Kornblith et al., 2003). In the same study, many women reported continuing to experience conditioned nausea,

vomiting, and psychological distress triggered by sights, smells, and tastes that reminded them of treatment (Kornblith et al., 2003).

In addition to decrements in physical and psychological quality of life, many survivors are also faced with challenges related to employment, finances, and interpersonal relationships. As part of a three year follow-up study, Ganz and colleagues (1996) found that a majority of breast cancer survivors were employed or actively engaged in volunteer work. However, emotional distress associated with work-place re-entry, illness disclosure to their boss and peers, and fear of obtaining future insurance coverage are commonly reported (Dow, Ferrell, Leigh, Ly & Gulasekaram, 1996; Ganz et al., 1996). Along with work-related concerns, the financial burden associated with cancer treatment and long-term follow-up care place additional stress on women and their families (Kornblith et al., 2003). Not surprisingly, marital distress is common among breast cancer survivors. Research supports that between 25 and 35% of breast cancer survivors experience relationship distress (Yang & Schuler, 2009). Relationship distress is also associated with worse psychological outcomes, slowed recovery, and a decline in overall physical activity (Yang & Schuler, 2009). Moreover, women in distressed relationships have continuously heightened levels of global stress, deteriorating health behaviors, and slower improvements in cancer-specific stress as compared to women in non-distressed relationships (Yang & Schuler, 2009).

Sexuality and Breast Cancer Survivorship

While a proportion of the physical, emotional, and interpersonal disruptions associated with diagnosis and treatment for breast cancer may improve over time, research has consistently documented the persistence and severity of sexual problems among survivors (Dizon, 2009). In addition to leading to sexual dysfunction, breast cancer can have a devastating impact on

women's broader sexual experiences, including their sexual identity and intimate behaviors. For most adult women, regardless of health status, sexuality plays an integral role in how they view and express themselves as individuals and partners in an intimate relationship. Therefore the impact of cancer on women's sexual experiences is not limited to changes in specific sexual behaviors (e.g., frequency of orgasm), but also includes changes in women's feelings of sexual attraction, sexual desire, intimacy, physical sensation, and emotional expression (Kissane, White, Cooper, & Vitetta, 2004).

For breast cancer survivors, sexual problems are one of the most common and distressing sequelae of cancer and its treatment. Indeed, a recent review of the literature found that from 30 to 100% of breast cancer survivors experience sexual dysfunction after treatment (Krychamn et al., 2006). Research in this area suggests that decreased sexual interest and arousal are among the most frequently reported sexual problems, affecting 56% and 47% of women respectively (Fobair & Spiegal, 2009). Additionally, genital pain during sexual activity, difficulty achieving orgasm, and decreased frequency of sexual intercourse are common concerns for breast cancer survivors and their partners (Meyerowitz, Desmond, Rowland, Wyatt, & Ganz, 1999).

Many women also experience changes in their ability to engage in and enjoy a range of sexual activities. For example, breast cancer survivors often report increased distress associated with undressing in front of their partner, discomfort having sex in the nude, and feeling less sexually attractive as a result of treatment for cancer (Ganz et al., 1996; Meyerowitz et al., 1999). Several studies have also identified behavioral changes in women's post-treatment patterns of sexual activity. Meyerowitz and colleagues (1999) found that one fourth of sexually active breast cancer survivors reported a post-treatment decline in the range of sexual activities they engaged in with their partners. Similar patterns emerged in a study by Ganz and colleagues

(1996) which found a substantial decrease in the frequency of physically affectionate behaviors such as kissing, embracing or touching between women and their partners following treatment.

For a proportion of women, sexual problems persist and worsen over time. In a longitudinal study of breast cancer survivors, Ganz and colleagues (1996) found a significant decline in women's sexual functioning during the first year of survivorship. Follow-up assessments completed at two and three years post-treatment confirmed that for many women, sexual problems such as vaginal dryness, decreased desire, difficulty reaching orgasm, and reduced frequency of sexual activity, worsened over time (Ganz et al., 1996). Similar rates of sexual dysfunction were found among breast cancer survivors assessed five years after diagnosis. Specifically, 56% of women reported decreased sexual desire, 38% experienced difficulty achieving orgasm, 49% reported vaginal dryness during sexual activity, and 35% reported that they were still unable to relax and enjoy sex (Fobair & Spiegel, 2009).

Left untreated, sexual problems have a profound impact on breast cancer survivors' emotional well-being and intimate partner relationships. Among survivors who experience negative changes in their sexual functioning, 62% report feelings of loss, worry, and guilt related to their sexual problems (Archibald, Lemieux, Byers, Tamlyn, & Worth, 2006). Anger, frustration, and resentment for having to cope with sexual dysfunction as a result of treatment are also common (Archibald et al., 2006). Additionally, many women worry about the effect of sexual dysfunction on their romantic relationships. Archibald and colleagues (2006) found that among breast cancer survivors who reported sexual dysfunction, 46% expressed guilt or concern over how these sexual changes had affected or were currently affecting their relationship with their partner.

Factors that Contribute to Sexual Dysfunction among Breast Cancer Survivors

Given the considerable prevalence and impact of sexual problems among breast cancer survivors, a growing body of research has identified a number of etiological factors that contribute to sexual dysfunction following treatment. For the most part, research in this area has focused on how medical or treatment-related variables affect post-treatment sexual outcomes. In particular, the impact of various surgical procedures on post-operative sexual function has been reviewed extensively in the literature.

Breast conserving surgery (BCS) is the least invasive surgical procedure used to treat early-stage breast cancer, removing only the tumor and surrounding tissue (Hunt, Robb, Strom, & Ueno, 2007). BCS is associated with more favorable outcomes, with women who receive BCS being more likely to resume intercourse in the months following surgery (Yurek, Farrar, & Andersen, 2000) and to report less post-operative sexual disruption than women treated with more extensive surgery. However, alterations in skin sensation, including numbness, tingling, or increased skin sensitivity are common side-effects of breast conserving surgery and may interfere with sexual activity (Kissane et al., 2004). For a proportion of women diagnosed with early-stage breast cancer, mastectomy (MRM) or surgical removal of the entire breast is necessary based on individual factors and tumor characteristics (Hunt et al., 2007). Compared to women treated with less invasive surgery, mastectomy patients have a greater risk of sexual problems, decreased arousal, and partial or permanent loss of nipple and skin sensation (Kissane et al., 2004).

While immediate or delayed breast reconstruction is an option for a majority of mastectomy patients, only a handful of studies have evaluated its impact on women's post-operative sexual experiences. In a study of surgically treated breast cancer survivors, Yurek and

colleagues (2000) found that compared to women who receive BCS or MRM, breast cancer survivors who had reconstructive surgery at the time of their mastectomy actually had the highest risk of post-operative sexual dysfunction (Yurek et al., 2000). Specifically, breast reconstruction patients were more likely to report difficulty achieving orgasm, decreased arousal, reduced frequency of sexual activity, decreased sexual satisfaction, and were less likely to resume sexual intercourse in the months following surgery than women treated with BCS or MRM (Yurek et al., 2000). Similar patterns of post-operative sexual disruption emerged in a study of mastectomy patients by Schover and colleagues (1995) who found a substantial decline in the frequency and pleasure associated with breast touching during sexual activity in women who received breast reconstruction compared to mastectomy-only patients. Despite the limited research available, these studies emphasize important differences in post-operative sexual outcomes between women who receive mastectomy and those who receive mastectomy plus breast reconstruction. Furthermore, these findings suggest that replacing or reconstructing the breast failed to improve sexual outcomes for a proportion of mastectomy patients, perhaps due to differences in appearance and sensation between the reconstructed breast(s) and their natural breasts, and that additional factors, such as body image concern, may place survivors at elevated risk for developing post-operative sexual dysfunction (Rowland et al., 2000).

In addition to surgery, the majority of women diagnosed with early stage breast cancer are treated with adjuvant chemotherapy, hormone therapy, or both. Research has consistently documented the deleterious effect of chemotherapy on women's sexual functioning. Among breast cancer survivors treated with adjuvant chemotherapy, 70% experience long-term sexual symptoms such as pain during intercourse (dyspareunia), inflammation and reduced vaginal wall tissue (vaginal atrophy), vaginal dryness, decreased vaginal depth, lack of sexual interest,

decreased arousal, and difficulty reaching orgasm (Basson, 2010). Additionally, common side-effects of chemotherapy, such as chronic pain, fatigue, and sleep disturbance also can interfere with sexual functioning (Archibald et al., 2006). Research has documented equally disruptive symptoms following hormone therapy. For women with hormone-receptor-positive breast cancers, hormone therapies are used to inhibit estrogen production associated with cancer cell growth (Hunt et al., 2007). As a result, estrogen deficiency and menopausal symptoms are common, which are associated with long-term sexual and reproductive symptoms including hot flushes, vaginal dryness, dyspareunia, decreased sexual desire, loss of genital sensitivity, vaginal atrophy, and pain and discomfort during intercourse (Basson, 2010; Mourits et al., 2002). Finally, some women experience medically-induced menopause as a result of surgery or cancer treatment, which has been associated with increased risk for adverse sexual outcomes including the development of sexual dysfunction (Dennerstein, Dudley, & Burger, 2001).

Several late and long-term side-effects of treatment also contribute to sexual problems among breast cancer survivors. For example, lymphedema is associated with decreased sexual activity, feeling less sexually attractive, and a lack of sexual interest (Ridner, 2009). Fatigue and chronic pain produce similarly disruptive sexual problems (Basson, 2010). Additionally, treatment with pain medications, benzodiazepines, selective serotonin-reuptake inhibitors (SSRIs), tricyclic antidepressants, and monoamine oxidase inhibitors for physical and psychological symptoms associated with cancer and its treatment are all common contributors to sexual dysfunction among breast cancer survivors (Basson, 2010).

While many studies have focused on the link between medical factors and post-treatment sexual outcomes, there is growing evidence that psychological factors such as anxiety and depression represent an additional risk factor for sexual dysfunction among survivors. In their

study of breast cancer survivors one to five years post-diagnosis, Ganz and colleagues (1999) found that women's psychological health strongly predicted sexual interest, sexual satisfaction, and sexual dysfunction. Among healthy women, depression and anxiety interfere with all phases of sexual response including desire, arousal, lubrication, and orgasm (Basson, 2010). Similar sexual problems are found among breast cancer survivors with clinically significant depression, anxiety, or both (Kissane et al., 2004). Finally, patterns of sexual behavior prior to cancer diagnosis and history of sexual dysfunction are important determinants of women's post-treatment sexual adjustment (Barni & Mondin, 1997; Ganz et al., 1999).

A number of studies have also documented the importance of women's partnered relationships to their long-term sexual adjustment. Indeed, research by Speer and colleagues (2005) found that the quality of women's partnered relationship was a stronger predictor of sexual functioning and satisfaction than treatment-induced changes in sexual functioning. In the same study, greater sexual problems, including decreased arousal, lubrication, orgasm, and sexual satisfaction were associated with increased relationship concern, poor partner communication and problem-solving, as well as general relationship distress (Speer et al., 2005). Thus, there is a clear interaction between women's sexual functioning and the quality of her partnered relationships. Similar results emerged from prospective research by Wimberly, Carver, Laurenceau, Harris, and Antoni (2005) who found that perceived partner sexual interest and emotional commitment strongly predicted women's long-term sexual adjustment.

Body Image Concern among Breast Cancer Survivors

Given the complex array of medical, psychological, and interpersonal factors that contribute to sexual problems among breast cancer survivors, it is important to understand and examine underlying mechanisms that explain these relationships. One potentially important

factor in understanding women's sexual adjustment following cancer is body image concern. For example, physical changes in appearance as a result of cancer treatment may alter how women perceive themselves emotionally and sexually, and their bodies. As a result, survivors may experience increased body image concern, which in turn could fuel adverse sexual outcomes such as decreased sexual interest, avoidance of intimate behaviors, and dissatisfaction with their sexual relationship. Similarly, symptoms of anxiety and depression could fuel increased concern about one's appearance as well as dissatisfaction with cancer-related appearance changes.

Body image is a multi-faceted construct that encompasses how women perceive themselves and interact with others in their social network, and includes evaluative, cognitive, and behavioral components (Cash & Pruzinsky, 1990). For most women, their body, and their breasts in particular, are a symbol that define them as a woman, mother, and sexual partner (Wilmoth, 2001). Therefore, the impact of breast cancer and its treatment is not limited to changes in physical appearance, but also can include alterations in how survivors perceive themselves as women and partners in an intimate relationship.

For breast cancer survivors, body image concerns are common in the first year after diagnosis. Indeed, research supports that within seven months of diagnosis, 67% of women report body image concerns (Fobair & Spiegel, 2009). While body image dissatisfaction is common among women in the general population, diagnosis and treatment for breast cancer appears to increase women's risk of developing body image concerns. Indeed, compared to women of the same age without a history of cancer, breast cancer survivors were found to be more likely to experience body image dissatisfaction, self-consciousness, and general body image concerns (Falk Dahl, Reinertsen, Nesvold, Fossa, & Dahl, 2010).

For a sizable proportion of women, body image concerns present during the first year after diagnosis fail to improve over time (Falk Dahl et. al., 2010). In a study of breast cancer survivors three years after initial treatment, Ganz and colleagues (1996) found that 49% reported feeling embarrassed to show their body to others, 51% reported discomfort showing their scars to others, and 43% continued to report discomfort with cancer-related changes to their bodies. Another study by Falk Dahl and colleagues (2010) found similar patterns of body image concern four and seven years after initial treatment. Among survivors who reported significant body image concern four years after treatment, 68% continued to report body image concern three years later (Falk Dahl et. al., 2010). Overall, evidence supports that body image concerns are a long-term quality of life concern for many breast cancer survivors.

Not surprisingly, negative perceptions of one's body can have a significant impact on women's emotional well-being and interpersonal relationships (Falk Dahl et. al., 2010). Indeed, Pikler and Winterowd (2003) found that breast cancer survivors with heightened body image concern were less able to accept their diagnosis, adjust to treatment-related changes in their physical appearance, seek out additional social support, and remain hopeful about their future compared to women who felt better about their bodies. Another study found that among breast cancer survivors, increased body image concern was associated with higher rates of clinically significant anxiety and depression, chronic fatigue, and increased use of analgesic and psychotropic medications compared to survivors with less body image concern (Falk Dahl et. al., 2010). Additionally, qualitative research suggests that distorted cognitions and descriptions of their bodies as "broken", disfigured, or problematic are common and distressing for many survivors (Denieffe & Gooney, 2010; Lam & Fielding, 2003).

Cancer Specific Body Image Concerns

Thus, it is clear that in addition to experiencing elevated levels of general body image concerns (e.g., dissatisfaction with one's weight and/or shape), many survivors have body image concerns related to changes in their appearance as a result of their cancer treatment. Indeed, studies of breast cancer survivors have identified a number of specific body image issues that appear to be common following breast cancer treatment. Baxter and colleagues (2006) identified feelings of shame about one's body or other aspects of one's appearance due to changes as a result of cancer treatment (e.g., scarring, loss of hair, loss of a breast) as a frequent concern among breast cancer survivors. They also noted that many survivors had concerns about whether others noticed or saw their cancer-related appearance changes (e.g., concerns about others seeing their scars when changing or wearing a swimsuit, concerns about whether others would notice they were wearing a breast prosthesis); a construct they termed transparency concerns.

There is also evidence to suggest that a proportion of breast cancer survivors develop a severe and impairing preoccupation with cancer-related changes to their appearance, or dysmorphic appearance concern. Dysmorphic appearance concern involves a preoccupation with a perceived defect or defects in one's appearance and is characterized by such symptoms as having an intense dissatisfaction and embarrassment regarding the defect, compulsive checking of the defect and attempting to camouflage or hide the defect from others. Women may also seek medical treatment to correct the defect and avoid social activities due to body image concerns (Lambrou, Veale, & Wilson, 2012; Littleton, Axsom, & Pury, 2005; Phillips, McElroy, Keck, Pope, & Hudson, 1993; Rosen & Ramirez, 1998). Conceptually similar to body dysmorphic disorder (BDD), dysmorphic appearance concern in the context of cancer survivorship would refer to a preoccupation with a perceived defect in appearance as a result of

treatment, such as a mastectomy scar, that causes significant impairment in women's daily functioning and quality of life.

Supporting the existence of dysmorphic concern in breast cancer survivors, several studies have identified cognitive and affective processes as well as behavioral patterns consistent with dysmorphic appearance concern among survivors. Indeed, qualitative research reveals that a proportion of survivors report strong feelings of disgust, shame and embarrassment about changes in their appearance (Gallagher et al., 2009; Wilmoth, 2001). In addition, there is evidence to support that that a sizable proportion of survivors engage in excessive checking and camouflaging behaviors. For example, research by Gallagher and colleagues (2009) found that surgically treated breast cancer survivors reported regularly checking to make sure their chest looked even when wearing prostheses. Moreover, the checking behaviors persisted for years after surgery (Gallagher et al., 2009). Similarly, several qualitative studies have found that survivors report engaging in a number of strategies to camouflage appearance-related defects, including wearing a prosthesis as a way of concealing changes to their body shape (e.g., having excess tissue or a hollow chest wall as result of mastectomy), wearing make-up or jewelry to compensate for adverse changes to their appearance, and replacing their pre-cancer wardrobe with more conservative and looser fitting clothing in an effort to cover surgical scars or skin discoloration (Flynn et al., 2010; Gallagher et al., 2009; Thomas-MacLean, 2005). Finally, some women report discomfort in certain social situations due to changes in their appearance (e.g., believing that others are staring at their chest) or avoiding certain social situations where others may see their appearance defects (e.g., changing in a locker room; Hormes et al., 2008; Wilmoth, 2001). Taken together, these studies suggest that for a proportion of survivors, diagnosis and treatment for breast cancer led to the development of dysmorphic appearance concern.

Factors that Contribute to Body Image Concern among Breast Cancer Survivors

Given the prevalence and persistence of body image dissatisfaction, shame, and dysmorphic concern among breast cancer survivors, a growing body of research has identified medical, psychological, and interpersonal factors that contribute to the development and maintenance of body image concerns. As with the sexual dysfunction literature, existing research on body image concern among breast cancer survivors has primarily examined the relationship between body image and medical treatment factors. Most often, research has focused on the relationship between body image and various surgical procedures.

Not surprisingly, research has repeatedly found that surgical treatment for breast cancer is associated with significant psychological distress and body image disturbance (Helms, O'Hea, & Corso, 2008). Indeed, research by Wilmoth (2001) found that for many survivors, surgery was conceptualized as an assault on their body, removing the part of the body that nourished their children and defined them as a woman. With survival rates equivalent to mastectomy, many women chose to have breast conserving surgery because it is less invasive and most likely to preserve breast appearance (Hunt et al., 2007). However, body image concerns related to post-operative scarring, feeling less attractive, and making more negative judgments about themselves are common among women treated with BCS (Ogden & Lindridge, 2008).

Compared to women who receive BCS, women treated with mastectomy report higher levels of body shame, greater dissatisfaction with their overall appearance and surgical scars, concern about the obviousness of their cancer, greater attractiveness concerns, and are more likely to feel the need to keep their body hidden (Anagnostopoulos & Myrgianni, 2009; Baxter et al., 2006). As previously mentioned, a majority of women treated with mastectomy or bi-lateral mastectomy have the option of having breast reconstruction at the time of their initial surgery or

after treatment. Reaby (1998) found that the most frequently reported reasons for having breast reconstruction were related to body image concerns including the ability to expand clothing options, regain femininity, and to feel whole again. Although intuitively breast reconstruction should reduce body image concerns, evidence suggests that reconstructive surgery fails to improve overall body image for a significant proportion of breast cancer survivors (Falk Dahl et al., 2010). In a sample of women four years after treatment who received reconstructive surgery, only 14% reported a positive body image and 34% continued to report significant body image concern (Falk Dahl et al., 2010).

In addition, changes in appearance associated with chemotherapy, such as hair loss and weight gain, can also contribute to body image concerns in breast cancer survivors. For example, Goodwin and colleagues (1999) found that 84% of women gain weight as a result of adjuvant chemotherapy. Of women reporting significant weight gain, 20% gained more than 10kg (22 lbs) in the first year after diagnosis (Goodwin et al., 1999). Hair loss is yet another common and distressing side-effect of adjuvant chemotherapy. A study by Carelle and colleagues (2002) found that breast cancer survivors rank chemotherapy-induced hair loss as the most severe and psychologically distressing side-effect of treatment aside from the effect of treatment on their partner and families. Another study by Freedman (1994) found that survivors rated treatment-related hair loss as more psychologically distressing than the surgical removal of their breast. In the same study, women described how treatment-related hair loss was a public display of their illness that they were unable to conceal, as compared to their surgical scars which they could cover with clothing (Freedman, 1994). For a proportion of breast cancer survivors, body image concern associated with hair loss is severe and persists long after hair re-growth (Münstedt, Manthey, Sachsse, &Vahrson, 1997). Indeed, many women have to further

adjust to changes in color and texture of re-grown hair (Harcourt & Frith, 2008). For example, hair that was straight prior to treatment grows back curly, or previously blonde hair grows back much darker.

Research has documented equally disruptive symptoms following radiation therapy. Radiation therapy is associated with fibrosis, or skin hardening, in the area treated (breast and arm), skin discoloration, and loss of skin sensitivity (Basson, 2010). In a study of breast cancer survivors four years after treatment, Falk Dahl and colleagues (2010) found that women who experienced changes in their skin as a result of radiotherapy were significantly more likely to report increased body image concern compared to women who did not experience alterations in skin sensitivity and appearance related to radiotherapy (Falk Dahl et al., 2010).

While it is clear that body image concerns are strongly associated with medical treatment of the disease, a growing body of research has also identified psychological factors that contribute to long-term body image concern. For example, Speer and colleagues (2005) found that among breast cancer survivors, depression was related to body image concern. Specifically, women who reported symptoms of depression were significantly more likely to endorse a more negative perception of their bodies compared to non-depressed women (Speer et al., 2005). Similar patterns have emerged in studies of survivors who report symptoms of anxiety (Van Esch, Roukema,Van der Steeg, & De Vries, 2011). For example, Van Esch and colleagues (2011) found that anxiety is a strong predictor of post-treatment body image concern among women diagnosed and treated for breast cancer. Finally, psychological investment in appearance prior to diagnosis and treatment for breast cancer is a strong predictor of post-treatment body image disturbance (Moreira, Silva, & Canavarro, 2010). Moreira and colleagues (2010) found that women who placed greater importance on their physical appearance prior to treatment had

significantly more body image concerns after treatment than women who placed less initial value on their physical appearance. Moreover, increased investment in appearance was associated with greater fear of negative evaluations by others, and increased social anxiety and avoidance (Moreira et al., 2010).

Effect of Body Image Concern on Long-Term Sexual Adjustment in Breast Cancer Survivors

While research clearly supports that sexual problems and body image concerns are commonly associated with cancer and its treatment, only a handful of studies have directly examined the link between body image concern and long-term sexual adjustment in breast cancer survivors. It possible that for many survivors, changes in physical appearance associated with diagnosis and treatment for breast cancer may alter their perception of themselves as women and sexual partners, and subsequently increase their risk of developing or exacerbating existing body image concern. As a result, women may experience decreased sexual interest, reduced sexual activity, and general dissatisfaction with their sexual relationship. Supporting the possibility that body image concern may play a causal role in long-term sexual dysfunction among survivors, research conducted with healthy women in the general population suggests that greater body image concern is associated with lower sexual self-efficacy, lower sexual assertiveness, poorer sexual esteem, increased self-consciousness, and sexual avoidance (Pujols, Meston, & Seal, 2010; Wiederman, 1996).

While largely under-investigated, research evaluating the relationship between body image concern and sexual adjustment in breast cancer survivors supports that increased body image concern places a woman at risk for long-term sexual problems. For example, greater body image concern has been associated with increased rates of sexual dysfunction (Taylor et al.,

1985), reduced sexual interest (Ganz et al., 1999) and reduced sexual activity (Lindley, Vasa, Sawyer, & Winer, 1998). Another study of breast cancer survivors by Ganz and colleagues (1999) found a significant association between body image concern and decreased sexual satisfaction. Finally, several studies have found evidence that women with increased body image concern experience greater disruption in their sexual relationships. Specifically, greater body image concern has been associated with embarrassment in exposing one's body, avoidance of being touched by their partner, discomfort showing scars, sexual relationship dissatisfaction, sexual inhibition, avoidance of undressing in front of their partner, having sexual intercourse in the dark, and delayed resumption of sexual activity after treatment (Gerard, 1982; Kissane et al., 2004; Steginga, Occhipinti, Wilson, & Dunn, 1998; Yurek et al., 2000).

Limitations of Extant Research

Overall, research supports that body image concern and sexual dysfunction are two of the most common and distressing sequelae of cancer and its treatment. In spite of these findings, relatively few studies have directly examined the relationship between body image concern and long-term sexual adjustment in breast cancer survivors, and existing research has been characterized by several limitations. Most notably, there has been a lack of consensus among researchers regarding how body image and sexually-relevant constructs are operationally defined, which has led to inconsistent findings throughout the literature. For example, body image is often considered a secondary component of a broader psychological construct (e.g., quality of life) and used interchangeably with other measures of psychological adjustment (e.g., self-concept and attractiveness; Moreira et al., 2010; White, 2000). Similarly, many researchers have relied on overt sexual behaviors such as frequency of oral sex, masturbation, and intercourse to define breast cancer survivors' post-treatment sexual adjustment. As a result,

existing research has failed to adequately conceptualize the full range of sexual experiences endorsed as important by women including both explicit sexual activities (e.g., intercourse) and physically affectionate behaviors (e.g., kissing, hugging; Flynn et al., 2010) as well as women's satisfaction with their sexual experiences and relationships.

In addition to poorly defined constructs, existing research has been limited by the methods used to measure and assess body image and sexual functioning in breast cancer survivors. For example, many studies have relied on questionnaires developed for use among non-medical populations to evaluate body image concerns and sexual dysfunction in survivors. Not surprisingly, measures developed for use among the general population often fail to adequately capture the physical and psychological changes associated with treatment for cancer. Similarly, the quality of women's sexual experiences, sexual satisfaction, and overall sexual adjustment are often measured by the frequency of post-treatment sexual activity. Notably, many studies have found that frequency of sexual activity did not predict sexual satisfaction or sexual adjustment in breast cancer survivors (Wimberly et al., 2005). Additional methodological concerns have been reported by Yurek and colleagues (2000), who found questionnaire items such as "I feel sexually attractive" to be highly susceptible to subjective interpretation among researchers as constructs related to body image, sexuality, or both domains.

Finally, research on etiological factors that contribute to and maintain body image concerns and sexual problems in breast cancer survivors has largely focused on medical or treatment-related variables such as disease stage, surgical procedures, and receipt of adjuvant treatment (Moreira et al., 2010; Yurek et al., 2000; Zimmermann, Scott, & Heinrichs, 2010). In contrast, relatively little attention has been given to other side-effects of treatment that also interfere with women's ability to engage in and enjoy a range of sexual activities. For example,

fatigue, treatment-related hair loss, and chronic pain have all been found to adversely affect women's post-treatment sexual experiences (Flynn et al., 2010). In addition to medical symptoms, psychosocial stressors are highly prevalent yet often overlooked factors associated with body image concerns and sexual dysfunction in breast cancer survivors. Lastly, body image and sexual functioning both include cognitive components (e.g., distorted thoughts and beliefs) which are rarely evaluated and warrant further attention. In sum, additional research is needed to adequately conceptualize the relationship between etiological factors that precipitate and maintain body image concerns and sexual dysfunction among breast cancer survivors as well as the extent to which body image concerns relate to sexual dysfunction.

Purpose of the Current Study

The purpose of the current study is to address some of the limitations of extant research assessing body image concerns and long-term sexual adjustment among breast cancer survivors. A national sample of breast cancer survivors was recruited to complete an online study evaluating cognitive, affective, and behavioral components of women's body image and sexual experiences. This study is one of the first to evaluate the extent to which body image concerns predict sexual functioning and satisfaction above that of cancer treatment variables.

In addition, factors that potentially mediate the relationship between body image and long-term sexual adjustment in breast cancer survivors were explored. For example, sexual activity inherently creates a focus on the body, and for women with existing appearance concerns, the additional focus on their body during sexual activity may amplify existing body image concerns, and as a result, negatively affect their sexual performance and satisfaction with the sexual experience. Supporting this possibility, prior research in a college sample of women found that increased appearance concerns during sexual activity was associated with decreased

sexual desire, less frequent orgasms, decreased arousal, and less sexual satisfaction (Cash, Maikkula, & Yamamiya, 2004). Furthermore, researchers found that contextually-specific body image concerns (e.g., during sexual activity) were a better predictor of women's sexual experiences than dispositional body image dissatisfaction (Cash et al., 2004). Therefore one goal of the current study was to expand upon previous research by examining sexually-specific body image concerns as a potential mediator of the relationship between body image concern and post-treatment sexual functioning.

Finally, body image concerns are common and distressing for many breast cancer survivors, yet little is known about how specific changes in appearance as result of cancer treatment affect women's perception of themselves and their bodies, and how this potentially influences their ability to engage in and enjoy a range of sexual experiences. Evidence from qualitative research supports that survivors frequently report that treatment-related weight gain, scarring, and changes in skin pigmentation affect their body image and reduce their motivation to engage in sexual activities with a partner (Flynn et al., 2010). However, further research is needed to quantify and evaluate the frequency and severity of symptoms. Thus, another goal of the current study was to examine body image as a potential mediator of the relationship between cancer-related changes in appearance and sexual functioning in breast cancer survivors.

Study Goals and Hypothesis

The current study had four primary goals. The first goal was to examine the frequency of body image concern and sexual problems among women diagnosed and treated for early-stage breast cancer.

Hypothesis 1: Survivors will report high levels of body image concern, as evidenced by elevated levels of body shame, high levels of transparency, high levels of body image concerns during sexual activity, and elevated dysmorphic appearance concern.

Hypothesis 2: Survivors will report high levels of sexual difficulties, as evidenced by a high incidence of sexual dysfunction and high levels of sexual dissatisfaction.

The second goal was to examine if body image concerns predict sexual difficulties after controlling for demographics, cancer treatment variables (e.g., disease stage, type of surgery, adjuvant treatment history, time since diagnosis, and menstrual status) and general distress.

Hypothesis 3: Body image (body shame, transparency, and dysmorphic concern) will predict sexual problems (sexual dysfunction and sexual dissatisfaction) above that of demographics, cancer variables (disease stage, type of surgery, adjuvant treatment history, time since diagnosis, and menstrual status), and general distress.

The third goal was to examine body image as a mediator of the relationship between cancer-related appearance changes and sexual adjustment.

Hypothesis 4: Body image (body shame, transparency, and dysmorphic concern) will mediate the relationship between cancer-related changes in appearance and post-treatment sexual adjustment (sexual dysfunction and sexual dissatisfaction).

The fourth goal was to examine body image concerns during sexual activity as a mediator of the relationship between body image concerns and long-term sexual adjustment.

Hypothesis 5: Body image concern during sexual activity will mediate the relationship between body image (body shame, transparency, and dysmorphic concern) and post-treatment sexual adjustment (sexual dysfunction and sexual dissatisfaction).

CHAPTER II: METHOD

Participants

Participants in this study were 219 breast cancer survivors recruited from a variety of breast cancer websites and social networking forums who completed a confidential online survey on body image concerns and post-treatment sexual adjustment. Women in this sample were between the ages of 22 and 81 years old with a mean age of 47.3 years (*SD* = 11.1 years). Among participants, 196 (89.5%) described themselves as European American, 10 (4.6%) as African American, 4 (1.8%) as Latina, 3 (1.4%) as Native American, 1 (0.5%) as Asian American, 1 (0.5%) as multi-ethnic and 4 (1.8%) described themselves as being of another ethnicity (e.g., Cape Verdean, English, or Mexican American). A total of 180 (82.2%) women were married or co-habitating with the remainder of the sample reporting that they were single (5.0%), dating (1.8%), separated (2.7%), divorced (2.7%), or widowed (1.8%). The majority of women in this sample were heterosexual (91.8%), well-educated (66.2% had completed post-secondary education), diagnosed with Stage II breast cancer (50.2%), had a mastectomy (69.4%), and subsequently received adjuvant treatment of chemotherapy (58.3%) and hormone therapy (62.5%). Time since diagnosis ranged from 4 months to 31 years, with an average of 4.4 years.

A total of 236 women consented to participate in the study; however, 17 (7.2%) participants were excluded from subsequent analyses due to partial or incomplete data. Among those excluded, items completed ranged from 1 to 17 items with an average of 6 completed items on the survey.

Measures

Demographic Information and Cancer Treatment History. Information on socio-demographics, current relationship status and cancer treatment history (e.g., disease stage, type

of surgery, adjuvant treatment history, time since diagnosis, and menstrual status) were obtained by a brief questionnaire developed for use in the current study (see Appendix A).

Sexual Dissatisfaction. Sexual dissatisfaction was assessed with the satisfaction subscale of the Female Sexuality Questionnaire (FSQ; Holmes, Clemmens, & Froman, 2000). This subscale consists of nine items designed to evaluate the physical and affective components of sexual dissatisfaction. For each item, participants are asked to indicate their level of agreement with the statement on a 5-point Likert scale bounded by 1 (*strongly disagree*) and 5 (*strongly agree*). A sample item is "I feel disappointed when I think about my sexual experiences." Scores can range from 9 to 45, with lower scores indicating less sexual satisfaction. Cronbach's alpha in the current study was 0.85. Subscale items are listed in Appendix B.

Changes in Appearance Related to Cancer Treatment. Participants were asked about changes in their appearance they experienced as a result of their diagnosis and treatment for breast cancer. A brief 13-item questionnaire was developed for use in the current study and asked participants to indicate whether or not they have experienced changes in hair color or texture, finger nails, weight, hair loss, skin (e.g., dryness, radiation burns, scarring, dyspigmentation, fibrosis), and lymphedema. Cancer-related changes in appearance were rated as present or absent. Item content was developed from the literature and included both qualitative and quantitative sources (Brady et al., 1997; Denieffe & Gooney, 2010; Falk Dahl et al., 2010; Kissane et al., 2004). Responses for each item were scored as Yes = 1 and No = 0, and summed to give a total score with higher scores indicating a greater number of changes in appearance as a result of diagnosis and treatment for breast cancer. Questionnaire items are listed in Appendix B.

Psychological Distress. The 21-item version of the Depression Anxiety Stress Scale **(**DASS; Lovibond & Lovibond, 1995) was administered to assess general psychological distress. The DASS is designed to measure current symptoms of depression (I couldn't seem to experience any positive feeling at all), anxiety (I felt I was close to panic), and stress (I found it difficult to relax). For each item, participants rated how often they have felt in the described manner in the past week on a 4-point scale bounded by 0 (*Did not apply to me at all*) and 3 (*Applied to me very much or most of the time*). Scores can range from 0 to 42 with higher scores indicating greater levels of distress. Cronbach's alpha among a non-clinical sample was 0.93 for the total scale (Henry & Crawford, 2005). Cronbach's alpha in the current study was 0.95. Supporting the measure's validity, scores have been found to correlate with other well-validated measures of depressive and anxiety symptoms (Brown, Chorpita, Korotitsch, & Barlow, 1997). Questionnaire items are listed in Appendix B.

Cancer-Related Body Image Concerns. Concerns about body image after diagnosis and treatment for breast cancer were assessed utilizing two subscales from the Body Image after Breast Cancer Questionnaire (BIBCQ; Baxter et al., 2006). Concern about the obviousness of cancer-related changes in appearance to others (I feel that people are looking at my chest) was assessed with the transparency subscale. Body shame was assessed with the body stigma subscale (The appearance of my breast could disturb others). Cronbach's alpha in a sample of breast cancer survivors was 0.77 for the transparency scale and 0.85 for the body stigma scale with a 2 week test-rest reliability of 0.82 and 0.84, respectively (Baxter et al., 2006). Cronbach's alpha in the current study was 0.74 for the body stigma scale and 0.77 for the transparency scale. Supporting the validity of the measure, subscales of the BIBCQ have been found to discriminate

women treated for breast cancer and women without a history of cancer (Baxter et al., 2006). Questionnaire items are listed in Appendix B.

Body Image Concerns during Sexual Activities. The 28-item Body Exposure during Sexual Activities Questionnaire (BESAQ; Cash 2004; Hangen & Cash, 1991) was administered to assess body image concerns during sexual activity. A sample item is, "I prefer to keep my body hidden under a sheet or blanket during sexual activity." For each item, individuals rate how characteristic the statement is of their experiences during sexual activity on a 5-point scale bounded by 0 (*Never*) and 4 (*Almost always/always*). Cronbach's alpha for the measure in sample of college women was 0.96 (Cash et al., 2004), and in the current study was 0.87. Supporting the validity of the measure, scores have been found to correlate moderately with other measures of body image in college samples (Cash et al., 2004). The questionnaire items are listed in Appendix B.

Dysmorphic Appearance Concern. Dysmorphic appearance concern was assessed using the Body Image Concern Inventory (BICI; Littleton et al., 2005). The BICI is a 19-item self-report measure designed to assess aspects of dysmorphic appearance concern including appearance dissatisfaction, compulsive checking of appearance defects, attempts to camouflage defects, seeking cosmetic treatment to correct the defect, interference in functioning related to appearance concerns, and avoidance of viewing oneself due to appearance concerns. For each item, participants indicate how often they have felt in the described manner or performed the described behavior on a 5-point scale anchored by 1 (*Never*) and 5 (*Always*). A sample item is, "I spend a significant amount of time checking my appearance in the mirror." In a sample of college women, Cronbach's alpha for the measure was 0.93, and in a community sample was 0.94 (Littleton et al., 2005; Littleton & Breitkopf, 2008). In the current study, Cronbach's alpha

for this measure was 0.93. Supporting the validity of the measure, scores have been found to discriminate individuals with subclinical symptoms of dysmorphic concern from individuals with clinically significant body dysmorphic symptomatology and to correlate with other self-report and interview measures of dysmorphic appearance concern (Littleton et al., 2005; Littleton & Breitkopf, 2008). The questionnaire items are listed in Appendix B.

Sexual Dysfunction. The Female Sexual Function Index (FSFI; Rosen et al., 2000) was administered to assess sexual dysfunction. The FSFI is a 19-item scale that assesses sexual dysfunction over the past four weeks and includes items assessing sexual desire, arousal, lubrication, orgasm, satisfaction, and pain. A sample item is, "Over the past four weeks, how would you rate your level or degree of sexual desire or interest?" Scores can range from 2 to 36 with higher scores indicating better sexual functioning. Cronbach's alpha of the measure in community and patient samples has ranged from 0.89 to 0.97 with 2 week test-retest reliabilities ranging from 0.79 to 0.86 (Rosen et al., 2000). Cronbach's alpha in the current study was 0.93. Supporting the validity of the measure, the FSFI has been found to differentiate between non-clinical populations and women diagnosed with a sexual arousal disorder (Rosen et al., 2000). Consistent with prior research using this measure (Baser, Li, & Carter, 2012), women who reported no sexual activity in the past month, as evidenced by 8 or more responses of 0 on the FSFI were exclude from analyses of this measure. This resulted in 50 women (32% of the sample) from being excluded from these analyses. The questionnaire items are listed in Appendix B.

Perspectives on Body Image and Sexuality after Breast Cancer. Two open-ended questions regarding survivors' thoughts or feelings about how their body image and sexuality had changed since being diagnosed with breast cancer were included. Specifically, these items

asked women to describe their thoughts or feelings about how their body image and sexuality had changed since being diagnosed with breast cancer. A total of 171 (78.0%) and 170 (77.6%) women provided written responses to the body image and sexuality questions respectively.

Procedures

Women were recruited from a variety of websites, including online breast cancer support groups and social networking sites (e.g., Facebook, twitter). Agreements were obtained from the Y-Me National Breast Cancer Organization Network of Strength Discussion Board, Susan G. Komen Discussion Forum, Pink Pearls of Hope Breast Cancer Organization, Carolina Breast Friends, FORCE: Facing Our Risk of Cancer Empowered, Bosom Buddies, Between Women, the UCLA Young Breast Cancer Survivorship Program, Young Survivor Sisters and several regional chapters of the Sister's Network, to post information about the study. Posted advertisements for the study stated that participants would be asked to complete a confidential online survey about body image and sexual functioning after treatment for breast cancer. The text of this advertisement is included in Appendix C.

Academic medical centers and cancer care coordinators at various cancer treatment centers were also contacted and agreed to distribute flyers about the study in their clinics. A study flyer is included in Appendix D. Several support group leaders passed out research flyers at meetings or emailed members a brief announcement about the research in their monthly publications. Information about the study was also communicated to potential participants by community leaders via twitter. Additionally, breast cancer advocates and authors of several popular breast cancer blogs were contacted and subsequently agreed to post information about the study on their websites.

A Facebook page was also created for the study and included a brief description about the study and a direct link to the online survey. A screenshot of the study Facebook page is included in Appendix E. Additionally, a paid Facebook advertisement was used to target members of breast cancer awareness groups and would appear on the side of their screen when logged into Facebook. A screenshot of the Facebook advertisement is included in Appendix F.

Interested women were directed to a link to a confidential online survey supported by Qualtrics, a software program for web-based survey research. Potential participants were given a brief description of the study and information about available national support services for breast cancer survivors and asked to provide electronic consent. The text of the consent form can be found in Appendix G. Individuals who consented to participate then completed the online survey which included questions regarding demographic information, cancer diagnosis and treatment, and information about the participants' post-treatment sexual experiences. Participants also completed self-report measures of body image and current psychological distress. Overall, the survey included 139 items and took the average participant approximately thirty minutes to complete. Upon completion of the survey, participants were asked to provide their email address to be entered in a gift card drawing. Email addresses were removed from the database prior to downloading.

There was no compensation offered for completing the survey, but a total of 15 women were selected from a random drawing to receive a $25.00 Walmart gift card. A copy of the ECU IRB approval letter for the study is included in Appendix A.

Analysis Plan

Hypothesis 1: It was hypothesized that women would report high levels of body image concern, as evidenced by scoring similarly to other breast cancer samples or at least 0.5 standard

deviation higher than community samples on the measures of body shame, transparency, body image concerns during sexual activity, and dysmorphic appearance concern.

To evaluate hypothesis 1, participants' scores on each of the body image measures were calculated. Participants' scores on these measures were then compared to published means for cancer and non-cancer samples. Specifically, participants' scores on the body stigma and transparency subscale of the BIBCQ were calculated and compared to the published means from another sample of early-stage breast cancer survivors (Baxter et al., 2006). Body image concerns during sexual activity was measured with the BESAQ and participants' total scale scores were calculated and compared with published means from a sample of sexually active women from the general population (Lowder, Ghetti, Moalli, Zyczynski, & Cash, 2010). Finally, dysmorphic appearance concern was evaluated with the BICI and participants' total scale scores were compared to published means from a community sample of European American women (Littleton & Breitkopf, 2008). In addition, the percentage of women who scored above the proposed clinical cut-off on the BICI was calculated.

Hypothesis 2: It was hypothesized that women would report high levels of sexual difficulties, as evidenced by scoring similarly to other breast cancer samples on the measures of sexual dysfunction and sexual dissatisfaction.

To evaluate this hypothesis, participants' score on the measure of sexual dysfunction was calculated. Specifically, women's sexual dysfunction was assessed with the FSFI and participants' subscale scores were summed to get a total score which was compared to published means from a sample of early-stage breast cancer survivors (Speer et al., 2005). Additionally, the percentage of women who scored above the proposed clinical cut-off on the FSFI was calculated.

Hypothesis 3: It was hypothesized that body image (body shame, transparency, and dysmorphic concern) would predict sexual problems (sexual dysfunction and sexual dissatisfaction) above that of demographics, cancer variables (disease stage, type of surgery, adjuvant treatment history, time since diagnosis, and menstrual status), and general distress.

In order to evaluate hypothesis 3, a hierarchical regression procedure was performed with total scores on the sexual adjustment variables (sexual dysfunction and sexual dissatisfaction) as the dependent variables. At step one, demographic information (e.g., ethnicity, SES, education) were entered into the model with dummy variables. For each dummy variable a score of 0 indicated that the participant did not belong to the group represented by that dummy variable and a score of 1 indicated that the participant belonged to the group represented by that dummy variable. For ethnicity, European Americans were used as the reference group and compared to all other ethnic minority backgrounds. SES was divided into 3 groups based on self-reported income (income levels of $100,000 and above [reference group]/low-mid incomes $45,000 or less/ mid-level incomes of $45,000-$100,000). Similarly, education was divided into 3 groups (college or professional degree [reference group]/high school degree or less education/some college education). At step two, the cancer treatment variables: disease stage, type of surgery, adjuvant treatment history, time since diagnosis, and menstrual status were entered. Disease stage was divided into 3 groups (stage I breast cancer [reference group]/stage II/stage III cancers). Participants who received a lumpectomy, mastectomy, mastectomy plus reconstruction, radiation, chemotherapy or hormone therapy were compared to women who had not received that type of cancer treatment [reference group]. Menstrual status was also divided into 3 groups (still menstruating [reference group]/no longer menstruating due to natural menopause/no longer menstruating due to medical interventions). Finally time since diagnosis was divided into 3

groups (0-2 years /2.1-4.9 years/5 years or more years [reference group]). At step three, total scores on the measure of general distress (DASS-21) were entered. Finally, at step 4, total scores on each of the body image measures (e.g., body shame, transparency, and dysmorphic concern) were entered. Separate regressions were conducted for the two sexual adjustment variables.

Hypothesis 4 stated that body image (body shame, transparency, and dysmorphic concern) would mediate the relationship between cancer-related changes in appearance and post-treatment sexual adjustment (sexual dysfunction and sexual dissatisfaction).

Hypothesis five stated that body image concern during sexual activity would mediate the relationship between body image (body shame, transparency, and dysmorphic concern) and post-treatment sexual adjustment (sexual dysfunction and sexual dissatisfaction).

To conduct these mediation analyses, the bootstrapping procedure developed by Preacher and Hayes (2004) and recommended by Fritz and MacKinnon (2007) was utilized. Bootstrapping is a statistical technique that uses sampling with replacement to create an estimate for the model paths (the *a*, *b*, *c'* paths) and produce a 95% confidence interval of these estimates. Additionally, this procedure allows for the evaluation of the significance of the mediated path by producing an estimate and 95% confidence interval for the overall mediated path (the *a* x *b* path). If the confidence interval does not include 0, then the model path is significant at $p < .05$. Compared to methods of mediation outlined by Baron and Kenny (1986), the bootstrapping procedure by Preacher and Hayes (2004) has several advantages in that it tests all paths of the model at the same time rather than through a series of separate regression analyses and does not require a normal sampling distribution of the indirect effect, thereby decreasing the likelihood of Type I error (Preacher & Hayes, 2004).

All analyses were conducted with MPlus statistical software (version 6.1; Muthén & Muthén, 1998–2010). For each hypothesis, a total of 1,000 draws were used to conduct each analysis as it considered the minimum number necessary to achieve an accurate estimate of the 95% confidence interval (Edwards & Lambert, 2007). To test hypothesis 4, four separate analyses were performed to evaluate the three body image variables (body shame, transparency, and dysmorphic concern) as mediators of the relationship between cancer-related changes in appearance and post-treatment sexual dysfunction. Four additional analyses were performed to evaluate the three body image variables (body shame, transparency, and dysmorphic concern) as mediators of the relationship between cancer-related changes in appearance and sexual dissatisfaction.

Finally, to test hypothesis 5, four separate analyses were performed to evaluate body image concern during sexual activity as a mediator of the relationship between the three body image variables (e.g., body shame, transparency, and dysmorphic concern) and sexual dysfunction. Additionally, four analyses were conducted to evaluate body image concern during sexual activity as a mediator of the relationship between sexual dissatisfaction and the three body image variables (e.g., body shame, transparency, and dysmorphic concern).

CHAPTER III: RESULTS

Descriptive Analyses

Demographic information is summarized in Table 1. Of the 236 breast cancer survivors who consented to participate in the study, 219 women completed the online questionnaire. Participants in this study were between the ages of 22 and 81 (mean age of 47.3 years, *SD* = 11.1 years) and were predominantly European American, married and well-educated with 66.2% of women having graduated from college or professional school. A majority of women in this sample were initially diagnosed with Stage I or II breast cancer, had a mastectomy on at least one breast, and received adjuvant cancer treatment (e.g., chemotherapy, radiation). In addition, nearly two-thirds of survivors who participated in this research were no longer menstruating due to medical or surgical menopause related to their cancer treatment. Medical and cancer treatment history of participants are summarized in Table 2.

Table 1

Sociodemographic Characteristics of Study Sample

	n	%
Age (years)		
≤39	41	18.7
40-49	46	21.0
50-59	47	21.5
≥60	19	8.7
Not reported	66	30.1
Age (mean ± SD)	47.3 ± 11.1	
Ethnicity		
White	196	89.5

Non-White	23	10.5
Education		
High School	19	8.7
Some College	55	25.1
College Graduate or Professional School	145	66.2
Married	169	77.2
Annual Household Income		
<$45,000	42	19.2
$45,000-$100,000	85	38.8
>$100,000	87	39.7
Not Reported	5	2.3

Table 2

Medical and Cancer Treatment History of Participants

	n	%
Cancer Stage		
Stage I	88	40.2
Stage II	109	49.8
Stage III	20	9.0
Not Reported	2	1.0
Time Since Diagnosis (years) (mean ± *SD*)	4.4 ± 4.4	
Type of Surgery[a]		
Lumpectomy	114	52.1
Mastectomy without breast reconstruction	41	18.7
Mastectomy with breast reconstruction	111	50.7

Adjuvant Treatment [b]		
Radiation	104	47.7
Chemotherapy	127	58.3
Hormone Therapy	135	62.5
Partial Hysterectomy	44	20.2
Not Reported	1	0.5
Menstrual Status		
Still menstruating	47	21.5
Not menstruating, natural menopause	42	19.1
Not menstruating, medical menopause	122	55.7
Not reported	8	3.7

[a]Women may have had multiple surgical procedures as part of a treatment course.
[b]Women may have received multiple adjuvant therapies as part of a treatment course.

Prevalence of Specific Changes in Appearance due to Cancer Treatment

Overall, a majority of women in this sample experienced multiple changes in appearance as a result of their diagnosis and treatment for breast cancer. The prevalence of specific changes in appearance due to cancer treatment is reported in Table 3. The total number of cancer-related changes in appearance ranged from 0 to 10 with a mean score of 6.1 (*SD* = 2.2), indicating that a majority of women experienced multiple changes in their appearance due to cancer treatment. Indeed, 71.4% of women reported experiencing hair loss and another 54.1% reported differences in the thickness, color or texture of regrown hair. A total of 15.9% breast cancer survivors reported experiencing a change in the appearance or pigmentation of their genitals due to cancer treatment. More than half of the women (58.3%) experienced changes to the appearance of their finger nails and a majority of survivors experienced scarring due to treatment. Changes in weight were also common, with 79.6% of breast cancer survivors reporting an increase or decrease in their weight due to cancer treatment. Breast changes were also acknowledged by

74.9% women. Additionally, nearly one third of women (31%) reported experiencing lymphedema. Finally, a majority of women (66.3%) reported experiencing changes to the appearance and texture of their skin.

Table 3

Prevalence of Specific Changes in Appearance due to Cancer Treatment

	n	%
Hair loss	150	71.4
Regrown hair is different (thinner, color, texture)	113	54.1
Finger nails (brittle, discolored)	123	58.3
Weight (gain or loss)	168	79.6
Skin dryness	135	64.3
Genital dyspigmentation	33	15.9
Breast changes (size, shape, or color of my nipple and/or areola)	155	74.9
Lymphedema	65	31.0
Scarring	203	92.7
Skin changes in the area treated for breast cancer	138	66.3
Radiation burn, rash, teleangiectasies	71	32.4
Skin dyspigmentation	74	33.8
Fibrosis	59	26.9

Means and standard deviations for study variables for breast cancer survivors and comparison groups are summarized in Table 4. The majority of breast cancer survivors in this sample exhibited no clinically significant symptoms of depression, anxiety, or stress as evidenced by a mean scale score of 31.0 (*SD* = 26.5) on the DASS-21. A proportion of women endorsed mild to moderate levels of anxiety (*n* = 32, 16.5%), depression (*n* = 54, 27.8%), and stress (*n* = 40, 20.6%). More severe symptoms of anxiety, depression and stress were reported by 34 (17.5%), 27 (13.9%) and 30 (15.5%) participants respectively. Compared to mean scores

from sample of primary care patients, women in this study reported similar levels of psychological distress (d = 0.05; Gloster et al., 2008).

Table 4

Comparison of Women in the Current Sample to Women from other Community and Cancer Samples on Study Variables

	Study Sample			Comparison Sample				
	n	Mean	*SD*	*n*	Mean	*SD*	Cohen's *d*	Sample Description
Psychological Distress								
DASS-21 Total Score	194	31.0	26.5	222	29.8	20.6	0.05	Primary Care Patients[a]
Body Image Variables								
Body Shame	195	20.2	10.4	143	17.8	6.4	0.27	BC Survivors[b]
Transparency	198	12.5	4.7	157	6.8	2.9	1.42	BC Survivors[b]
Body Image Concerns during Sexual Activity	163	54.5	29.8	67	28.0	20.0	0.98	Healthy Women GP[c]
Dysmorphic Concern	175	53.6	15.0	321	46.8	14.5	0.47	Healthy Women GP[d]
Sexual Dysfunction and Dissatisfaction Variables								
Sexual Dysfunction	104	21.9	10.4	55	22.3	8.9	0.05	BC Survivors[e]
Sexual Dissatisfaction	201	25.8	9.2					

Note: BC stands for breast cancer. GP stands for general population.
[a] Gloster et al. (2008)
[b]Baxter et al. (2006)
[c]Lowder et al. (2010)
[d]Littleton & Breitkopf (2008)
[e]Speer et al. (2005)
[f]No normative sample data have been published

Hypothesis I

It was hypothesized that women would report high levels of body image concerns, as evidenced by high levels of body shame, high levels of transparency, high levels of body image concerns during sexual activity, and elevated dysmorphic appearance concern. Participants' scores supported this hypothesis and demonstrated a consistent pattern of elevated body image concerns across all measures. Body stigma scores ranged from 0 to 43 with a mean score of 20.2, indicating that women in this sample often experienced shame about their body. Compared to mean scores from another sample of breast cancer survivors, women in this study reported greater body shame (d = 0.27; Baxter et al., 2006). Similarly, concern about the obviousness of cancer-related changes in their appearance was also prevalent in this sample as evidenced by the mean score of 12.5 on the transparency scale. Results further suggest that survivors in this sample had greater transparency concerns compared to another sample of breast cancer survivors (d = 1.42; Baxter et al., 2006). Body image concerns during sexual activity scores were also high as evidenced by a mean score of 54.5 on the BESAQ which is higher than published means for women of a similar age without a history of cancer (d = 0.98; Lowder et al., 2010). Finally, mean scores of 53.6 on the dysmorphic concern measure indicated high levels of dysmorphic appearance concern with 26.3% of women scoring above the clinical cut-off (i.e., score of $\geq$ 72; Littleton et al., 2005). Additionally, mean scores supported that survivors in this study reported more dysmorphic appearance concerns than women from a community sample (d = 0.47; Littleton & Breitkopf, 2008). Measures of body image were also strongly correlated. Correlations among non-dichotomous variables included in this study are summarized in Table 5.

Hypothesis II

Hypothesis two predicted that women would report high levels of sexual difficulties, as evidenced by a high incidence of sexual dysfunction. Among sexually active survivors, sexual dysfunction was prevalent as indicated by the mean score of 21.9 for sexual dysfunction which is consistent with high rates of sexual dysfunction found in a similar sample of breast cancer survivors (d = 0.05; Speer et al., 2005). Clinical cut-off scores for sexual dysfunction were calculated, indicating that 69% (n = 72) of sexually active survivors in this sample met criteria for sexual dysfunction (i.e., score of $\leq$ 26; Rosen et al., 2000).

Sexual dissatisfaction scores covered the entire range of possible scores (from 9 to 45) with a mean score of 25.8, indicating moderate to low levels of sexual satisfaction. Comparison scores from another sample for the sexual satisfaction subscale of the FSQ were unavailable. Individual items on the sexual satisfaction subscale of the FSQ were evaluated and revealed that 59% of survivors in this sample were dissatisfied with their sex life and described their love life as disappointing. Many women in this sample also reported difficulties communicating with their sexual partners. Indeed, 84% of survivors reported feeling embarrassed talking to their partners about what sexually pleased them. Likewise, 61% reported difficulty telling their partner what they like and don't like sexually. In addition to being dissatisfied with their sex lives overall, 65% of women reported feeling unhappy with their current sexual behavior. For instance, nearly two-thirds of survivors in this sample described feeling disappointed when they think about their sexual experiences and only 45% reported that sex was fun for themselves and their partner. Finally, 45% reported that something was lacking in their sex life. Measures of sexual adjustment were also strongly correlated. Correlations among non-dichotomous variables included in this study are summarized in Table 5.

Table 5

Correlations between Non-Dichotomous Variables

	Body Shame	Transparency	Body Image Concerns during Sex	Dysmorphic Concern	Sexual Dysfunction	Sexual Dissatisfaction
Transparency	0.64**	___				
Body Image Concerns during Sex	0.81**	0.56**	___			
Dysmorphic Concern	0.63**	0.63**	0.64**	___		
Sexual Dysfunction	-0.32**	-0.16	-0.43**	-0.27**	___	
Sexual Dissatisfaction	-0.45**	-0.26**	-0.54**	-0.31**	0.68**	___
General Distress	0.34**	0.36**	0.29	0.49**	-0.25	-0.27**

**p < .01

Hypothesis III

It was hypothesized that body image (body shame, transparency, and dysmorphic concern) would predict sexual adjustment (sexual dysfunction and sexual dissatisfaction) above that of demographics, cancer variables (disease stage, type of surgery, adjuvant treatment history, time since diagnosis, and menstrual status), and general distress.

Results of the regression analyses for sexual dysfunction among the sub-sample of sexually active breast cancer survivors are presented in Table 6. Demographic variables entered in Step 1 of the model were not significant, ΔF (5,120) = 0.66, p = 0.65, ΔR^2 = 0.03. The set of cancer-related variables added to the model at step 2 resulted in a significant increase in variance explained, ΔF (12, 108) = 2.38, $p < 0.05$, ΔR^2 = 0.20. In Step 3, the addition of general distress to the model was also significant, ΔF (1, 107) = 21.04, $p < 0.001$, ΔR^2 = 0.13. However, addition of the body image variables at Step 4 resulted in a non-significant increase in the variance explained, ΔF (3, 104) = 2.43, p = 0.07, ΔR^2 = 0.04.

The regression analyses for sexual dissatisfaction among the sub-sample of sexually active survivors are presented in Table 7. Demographic variables entered in Step1 were non-significant, ΔF (5,136) = 0.62, p = 0.69, ΔR^2 = 0.02. In Step 2, addition of the cancer-related variables was significant, ΔF (12, 124) = 2.42, $p <0.05$, ΔR^2 = 0.19. At Step 3, general distress was added to the model and significantly added to the prediction of sexual dissatisfaction, ΔF (1,123) = 16.26, $p < 0.001$, ΔR^2 = 0.09. Unlike in the sexual dysfunction model, adding in the body image variables at Step 4, resulted in a significant increase in variance explained, ΔF (3,120) = 5.46, $p < 0.001$, ΔR^2 = 0.08.

Table 6

Results of Regression Analyses examining Body Image Variables as Predictors of Sexual Dysfunction

	R^2	ΔR^2	ΔF	*b*	β	sr^2	*p*
Step 1	0.03	0.03	0.66				
Demographic Variables							
Non-white Ethnicity				3.09	0.10	0.10	0.290
SES Low-Mid				1.99	0.08	0.07	0.466
SES Mid				2.69	0.13	0.11	0.211
Education-High School or less				-1.62	-0.44	-0.04	0.633
Education-Some College				0.28	0.12	0.01	0.906
Step 2	0.23	0.20	2.38*				
Cancer-related Variables							
Cancer Stage II				-2.22	-0.11	-0.10	0.302
Cancer Stage III				1.26	0.04	0.04	0.714
Lumpectomy				-1.38	-0.07	-0.06	0.565
Mastectomy				-0.43	-0.02	-0.01	0.888
Mastectomy plus Reconstruction				-4.28	-0.21	-0.15	0.132
Radiation				-2.33	-0.11	-0.10	0.295
Chemotherapy				-1.91	-0.09	-0.08	0.405
Hormone Therapy				-1.01	0.05	-0.05	0.600
Menstrual Status-natural menopause				-6.88	-0.26	-0.21	0.025
Menstrual Status-medical intervention				-7.69	-0.36	-0.28	0.003
Time since diagnosis (0-2 years)				3.00	0.14	0.14	0.145
Time since diagnosis (2.1-4.9 years)				-0.85	-0.03	-0.03	0.770
Step 3	0.36	0.13	21.04*				
General Distress				-0.14	-0.36	-0.40	0.001
Step 4	0.40	0.04	2.43				
Body Image Variables							
Body Shame				-0.19	-0.18	-0.14	0.200
Transparency				-0.03	-0.01	-0.01	0.991
Dysmorphic Concern				-0.16	-0.21	-0.18	0.102

*$p < .05$.

Table 7

Results of Regression Analyses Examining Body Image Variables as Predictors of Sexual Dissatisfaction

	R^2	ΔR^2	ΔF	*b*	β	sr^2	*p*
Step 1	0.02	0.02	0.62				
Demographic Variables							
Non-White Ethnicity				3.81	0.13	0.13	0.170
SES Low-Mid				-1.60	-0.07	-0.06	0.524
SES Mid				0.34	0.02	0.02	0.873
Education-High School or less				-1.62	-0.05	-0.05	0.612
Education-Some College				0.92	0.04	0.04	0.673
Step 2	0.21	0.19	2.42*				
Cancer-related Variables							
Cancer Stage II				1.68	0.09	0.08	0.370
Cancer Stage III				1.47	0.05	0.04	0.641
Lumpectomy				0.30	0.02	0.01	0.882
Mastectomy				0.50	0.02	0.02	0.852
Mastectomy plus Reconstruction				-2.85	-0.15	-0.10	0.254
Radiation				-1.89	-0.10	-0.09	0.332
Chemotherapy				0.86	0.04	0.04	0.670
Hormone Therapy				0.56	0.03	0.03	0.740
Menstrual Status-natural menopause				-5.34	-0.21	-0.18	0.042
Menstrual Status-medical intervention				-9.35	-0.48	-0.38	0.001
Time since diagnosis (0-2 years)				2.17	0.11	0.11	0.234
Time since diagnosis (2.1-4.9 years)				0.58	0.02	0.02	0.826
Step 3	0.30	0.09	16.26*				
General Distress				-0.13	-0.34	-0.34	0.001
Step 4	0.38	0.08	5.46*				
Body Image Variables							
Body Shame				-0.28	-0.30	-0.25	0.011
Transparency				-0.26	-0.13	-0.10	0.273
Dysmorphic Concern				0.06	0.09	0.07	0.457

*$p < .05$.

Hypothesis IV

Hypothesis four predicted that body image (body shame, transparency, and dysmorphic concern) would mediate the relationship between number of cancer-related changes in appearance and post-treatment sexual dysfunction and sexual dissatisfaction. Bias-corrected bootstrap estimates and 95% confidence intervals for the mediation analyses for cancer-related changes in appearance and sexual dissatisfaction are reported in Table 8. Results of the analyses indicated significant mediation for body shame, transparency, and dysmorphic concern, with higher levels of each body image variable mediating the relationship between higher total cancer-related changes in appearance and greater post-treatment sexual dissatisfaction. Specifically, the analysis including body shame as the mediator indicated that the paths from changes in appearance to body shame and body shame to sexual dissatisfaction were significant. The indirect path from changes in appearance to sexual dissatisfaction through body shame was also significant, with higher levels of body shame significantly mediating the relationship between greater number of cancer-related changes in appearance and higher sexual dissatisfaction. Transparency functioned similarly as a mediator of the changes in appearance-sexual dissatisfaction relationship, with higher levels of transparency significantly mediating the relationship between greater number of changes in appearance and higher levels of sexual dissatisfaction. The paths from greater number of changes in appearance to transparency and from greater transparency to greater sexual dissatisfaction were also significant. Dysmorphic concern was also found to significantly mediate the relationship between number of cancer-related changes in appearance and sexual dissatisfaction, with higher levels of dysmorphic appearance concern significantly mediating the relationship between greater number of cancer-related changes in appearance and higher levels of sexual dissatisfaction. The paths from greater

number of changes in appearance to higher levels of dysmorphic concern and higher levels of dysmorphic concern to higher levels of sexual dissatisfaction were also significant.

Table 8

Bias-Corrected Bootstrap Estimates and 95% Confidence Intervals (CIs) of the Unstandardized Estimates for Cancer-Related Changes in Appearance and Sexual Dissatisfaction Mediation Analyses

	Estimate	95% CI of estimate
Changes in Appearance/Body Shame/Sexual Dissatisfaction		
Changes in Appearance-Body Shame	1.03	**0.38, 1.71**
Body Shame-Sexual Dissatisfaction	-0.39	**-0.49, -0.27**
Changes in Appearance-Sexual Dissatisfaction (direct)	-0.03	-0.52, 0.51
Changes in Appearance-Sexual Dissatisfaction (indirect)	-0.41	**-0.74, -0.16**
Changes in Appearance/Transparency/Sexual Dissatisfaction		
Changes in Appearance-Transparency	0.51	**0.09, 0.80**
Transparency-Sexual Dissatisfaction	-0.43	**-0.70, -0.18**
Changes in Appearance-Sexual Dissatisfaction (direct)	-0.23	-0.79, 0.32
Changes in Appearance-Sexual Dissatisfaction (indirect)	-0.22	**-0.48, -0.04**
Changes in Appearance/Dysmorphic Concern/Sexual Dissatisfaction		
Changes in Appearance-Dysmorphic Concern	1.85	**0.77, 2.89**
Dysmorphic Concern-Sexual Dissatisfaction	-0.16	**-0.24, -0.05**
Changes in Appearance-Sexual Dissatisfaction (direct)	-0.12	-0.67, 0.44
Changes in Appearance-Sexual Dissatisfaction (indirect)	-0.29	**-0.55, -0.09**

Note. Confidence interval (CI) ranges in bold are statistically significant.

Body shame and dysmorphic concern significantly mediated the relationship between cancer-related changes in appearance and post-treatment sexual dysfunction. Bias-corrected bootstrap estimates and 95% confidence intervals for the mediation analyses for cancer-related

changes in appearance and sexual dysfunction are reported in Table 9. Specifically, the paths from greater number of changes in appearance to higher levels of body shame and higher levels of body shame to higher levels of sexual dysfunction were significant. The indirect path for changes in appearance to sexual dysfunction through body shame was also significant, with higher levels of body shame significantly mediating the relationship between greater number of cancer-related changes in appearance and higher levels of sexual dysfunction. In contrast, only the path from greater number of changes in appearance to higher levels of transparency was significant in that set of mediation analyses. Finally, dysmorphic concern functioned as a significant mediator of the relationship between changes in appearance and sexual dysfunction, with higher levels of dysmorphic concern significantly mediating the relationship between greater number of cancer-related changes in appearance and higher levels of sexual dysfunction. The paths from changes in appearance to dysmorphic concern, dysmorphic concern to sexual dysfunction, as well as the direct path from changes in appearance to sexual dysfunction were also significant.

Table 9

Bias-Corrected Bootstrap Estimates and 95% Confidence Intervals (CIs) of the Unstandardized Estimates for Cancer-Related Changes in Appearance and Sexual Dysfunction Mediation Analyses

	Estimate	95% CI of estimate
Changes in Appearance/Body Shame/Sexual Dysfunction		
Changes in Appearance-Body Shame	1.05	**0.40, 1.69**
Body Shame-Sexual Dysfunction	-0.31	**-0.47, -0.14**
Changes in Appearance-Sexual Dysfunction (direct)	-0.27	-1.12, 0.50

Changes in Appearance-Sexual Dysfunction (indirect)	-0.33	**-0.66, -0.11**
Changes in Appearance/Transparency/Sexual Dysfunction		
Changes in Appearance-Transparency	0.50	**0.09, 0.80**
Transparency-Sexual Dysfunction	-0.14	-0.59, 0.15
Changes in Appearance-Sexual Dysfunction (direct)	-0.62	-1.47, 0.23
Changes in Appearance-Sexual Dysfunction (indirect)	-0.07	-0.42, 0.06
Changes in Appearance/Dysmorphic Concern/Sexual Dysfunction		
Changes in Appearance-Dysmorphic Concern	1.92	**0.88, 2.93**
Dysmorphic Concern-Sexual Dysfunction	-0.19	**-0.30, -0.07**
Changes in Appearance-Sexual Dysfunction (direct)	-0.29	**-1.09, 0.59**
Changes in Appearance-Sexual Dysfunction (indirect)	-0.36	**-0.77, -0.14**

Note. Confidence interval (CI) ranges in bold are statistically significant.

Hypothesis V

Hypothesis five stated that body image concern during sexual activity would mediate the relationship between more general body image (e.g., body shame, transparency, and dysmorphic concern) and post-treatment sexual dysfunction and sexual dissatisfaction. Results from these mediation analyses indicated significant mediation, with higher levels of body image concerns during sexual activity mediating the relationship between higher levels of body shame, transparency, and dysmorphic concern and higher levels of sexual dissatisfaction and sexual dysfunction. Bias-corrected bootstrap estimates and 95% confidence intervals for the mediation analyses for body image concerns during sexual activity and sexual dissatisfaction are reported in Table 10. Higher levels of body image concern during sexual activity was found to significantly mediate the higher levels of body shame-higher levels of sexual dissatisfaction relationship. The paths from higher levels of body shame to higher levels of body image concerns during sexual activity and higher levels of body image during sexual activity to higher levels of sexual dissatisfaction were significant. In addition, higher levels of body image

concerns during sexual activity mediated the relationship between higher levels of transparency and higher levels of sexual dissatisfaction. Results from that mediation analysis indicated that the paths from higher levels of transparency to higher levels of body image concerns during sexual activity and higher levels of body image during sex to higher levels of sexual dissatisfaction were also significant. Body image concern during sexual activity also functioned as a mediator between dysmorphic appearance concern and sexual dissatisfaction, with higher levels of body image concerns during sexual activity significantly mediating the relationship between higher levels of dysmorphic appearance concerns and higher levels of sexual dissatisfaction. Results indicated that the paths from higher levels of dysmorphic concern to higher levels of body image concerns during sexual activity and higher levels of dysmorphic concern to higher levels of sexual dissatisfaction were significant.

Table 10

Bias-Corrected Bootstrap Estimates and 95% Confidence Intervals (CIs) of the Unstandardized Estimates for Body Image Concern during Sexual Activity and Sexual Dissatisfaction Mediation Analyses

	Estimate	95% CI of estimate
Body Shame/BIC during Sex/Sexual Dissatisfaction		
Body Shame-BIC during Sex	2.31	**2.07, 2.51**
BIC during Sex-Sexual Dissatisfaction	-0.15	**-0.21, -0.08**
Body Shame-Sexual Dissatisfaction (direct)	-0.06	-0.25, 0.17
Body Shame-Sexual Dissatisfaction (indirect)	-0.35	**-0.50, -0.20**
Transparency/BIC during Sex/Sexual Dissatisfaction		
Transparency-BIC during Sex	2.50	**1.12, 3.99**
BIC during Sex-Sexual Dissatisfaction	-0.16	**-0.21, -0.11**

Transparency-Sexual Dissatisfaction (direct)	-0.03	-0.27, 0.36
Transparency-Sexual Dissatisfaction (indirect)	-0.41	**-0.78, -0.16**
Dysmorphic Concern/BIC during Sex/Sexual Dissatisfaction		
Dysmorphic Concern-BIC during Sex	1.19	**0.97, 1.42**
BIC during Sex-Sexual Dissatisfaction	-0.18	**-0.23, -0.12**
Dysmorphic Concern-Sexual Dissatisfaction (direct)	0.04	-0.08, 0.14
Dysmorphic Concern-Sexual Dissatisfaction (indirect)	-0.21	**-0.29, -0.14**

Note. Confidence interval (CI) ranges in bold are statistically significant.
BIC During Sex = Body Image Concerns during Sexual Activity.

The final set of mediation analyses were significant, with higher levels of body image concern during sexual activity mediating the relationship between body shame, transparency, and dysmorphic concern and sexual dysfunction. Bias-corrected bootstrap estimates and 95% confidence intervals for the mediation analyses for body image concerns during sexual activity and sexual dysfunction are reported in Table 11.

Higher levels of body image concerns during sexual activity was found to significantly mediate the higher levels of body shame-higher levels of sexual dysfunction relationship. Furthermore, the paths from higher levels of body shame to higher levels of body image concerns during sexual activity and higher levels of body image concerns during sexual activity to higher levels of sexual dysfunction were significant. Body image concerns during sexual activity also functioned as a mediator between transparency and sexual dysfunction, with higher levels of body image concerns during sexual activity mediating the relationship between transparency and sexual dysfunction. Further analysis of the model found that the paths from higher levels of transparency to higher levels of body image concerns during sexual activity, higher levels of body image during sexual activity to higher levels of sexual dysfunction, as well as the direct path from higher levels of transparency to higher levels of sexual dysfunction were significant. In the final mediation analyses, body image concerns during sexual activity

significantly mediated the relationship between dysmorphic appearance concern and sexual dysfunction. The paths from higher levels of dysmorphic appearance concern to higher levels of body image concerns during sexual activity and higher levels of body image concern during sexual activity to higher levels of sexual dysfunction were significant.

Table 11

Bias-Corrected Bootstrap Estimates and 95% Confidence Intervals (CIs) of the Unstandardized Estimates for Body Image Concerns during Sexual Activity and Sexual Dysfunction Mediation Analyses

	Estimate	95% CI of estimate	
Body Shame/BIC during Sex/Sexual Dysfunction			
Body Shame-BIC during Sex	2.31	**2.10,**	**2.53**
BIC during Sex-Sexual Dysfunction	-0.15	**-0.24,**	**-0.06**
Body Shame-Sexual Dysfunction (direct)	0.02	-0.24,	0.24
Body Shame-Sexual Dysfunction (indirect)	-0.35	**-0.56,**	**-0.14**
Transparency/BIC during Sex/Sexual Dysfunction			
Transparency-BIC during Sex	2.48	**1.02,**	**3.97**
BIC during Sex-Sexual Dysfunction	-0.20	**-0.26,**	**-0.13**
Transparency-Sexual Dysfunction (direct)	0.46	**0.01,**	**0.79**
Transparency-Sexual Dysfunction (indirect)	-0.49	**-0.79,**	**-0.25**
Dysmorphic Concern/BIC during Sex/Sexual Dysfunction			
Dysmorphic Concern-BIC during Sex	1.21	**0.98,**	**1.42**
BIC during Sex-Sexual Dysfunction	-0.11	**-0.19,**	**-0.04**
Dysmorphic Concern-Sexual Dysfunction (direct)	-0.10	-0.29,	0.07
Dysmorphic Concern-Sexual Dysfunction (indirect)	-0.14	**-0.24,**	**-0.05**

Note. Confidence interval (CI) ranges in bold are statistically significant.
BIC during Sex = Body Image Concerns during Sexual Activity.

Survivors' Perceptions on Changes in their Body Image and Sexuality after Cancer

From this sample, 25 (14.6%) responses were randomly selected and examined for themes by the author. Themes were subsequently coded among these 25 respondents in order to provide an overview of women's perceptions of their body image and sexuality after diagnosis and treatment for breast cancer. Specifically, all responses were read by the author, and a comprehensive list of themes was developed. This list consisted of 7 body image-related themes (feelings of shame/embarrassment, existing body image concerns exacerbated by cancer treatment, negative perception of changes in appearance, greater appearance acceptance, negative perception of reconstructive surgery, unsupportive partner reactions, avoidance of viewing one's appearance) and 6 sexuality-related themes (shame/self-blame/embarrassment related to sexual problems, treatment-related sexual dysfunction, acceptance of changes in sexual functioning, interpersonal problems related to sexual difficulties, unsupportive partner reactions, avoidance of sexual activity). Each response was then coded for the presence of each theme. Evaluation of these themes provides a picture that is largely consistent with the body image data from hypothesis I. Women frequently described feelings of shame or embarrassment about their body, as well as feeling less feminine following cancer treatment. Likewise, women who described having body image concerns prior to their cancer treatment also reported increased body image concerns after treatment. Among responses sampled, 90% of women reported specific body image concerns related to weight gain or loss, scars, lymphedema, and breast disfigurement. Another common theme that emerged was that women reported struggling to accept their reconstructed breasts because they felt foreign or looked like "great fake boobs." Indeed, nearly 64% of women sampled who reported having reconstruction described "looking normal" when clothed but felt intensely self-conscious when nude. Interestingly, many of these

women described behavioral changes consistent with dysmorphic appearance concern such as camouflaging perceived defects with clothing, avoiding mirrors when nude, and making drastic changes to their wardrobe to accommodate their new appearance. Conversely, 20% of breast cancer survivors sampled described high levels of post-treatment appearance acceptance and minimal changes in their body image after cancer. Interestingly, the women who reported having a positive body image also described having strong social support from a partner in their open-ended responses.

The responses with regards to women's perceived changes in sexuality after cancer were also largely consistent with the data from hypothesis two. Survivors described feelings of shame, embarrassment, and self-blame related to decreased sexual desire and difficulties achieving orgasm. With regard to treatment-related sexual dysfunction, nearly 80% of women reported concerns about insufficient lubrication, which for many women led to painful intercourse or complete cessation of sexual activity. Loss of sensation in their chest or reconstructed breasts was another common problem reported by 64% of women sampled. A majority of women who reported sexual difficulties also reported comorbid intimate partner relationship problems or body image concerns related to sexual activity in their open-ended responses.

Consistent with the prevalence of sexual difficulties from self-report measures, a majority of women in the current study described sexual problems due to cancer and its treatment. Only a small fraction of women sampled reported experiencing no changes or positive changes in their sexual functioning after cancer. Nonetheless, several survivors in this sample reported feeling greater emotional intimacy with their partner after cancer. Similar to women who reported having a positive body image after treatment, breast cancer survivors who reported greater

emotional intimacy often attributed better sexual adjustment to factors such as having a positive relationship with their sexual partner and using adaptive communication strategies to openly discuss changes in sexuality with their partners.

CHAPTER IV: DISCUSSION

This study examined cognitive, affective, and behavioral components of women's body image and sexual functioning and satisfaction in a national sample of breast cancer survivors who completed an online survey. Women were predominantly European American, married, diagnosed with Stage I or II breast cancer, had a mastectomy, and received adjuvant treatment (e.g., chemotherapy, radiation). Demographic characteristics of this sample were similar to samples from other published studies on breast cancer survivors as a majority of women in these samples were European American, married and well-educated (Ganz et al., 1999; Ganz et al., 2002; Helms et al., 2008; Speer et al., 2005). However, women in this sample were younger and more likely to have had a mastectomy than women from several other breast cancer studies (Ganz et al., 1999; Ganz et al., 2002; Helms et al., 2008).

Consistent with prior research, a majority of breast cancer survivors in this sample experienced multiple changes in their appearance due to cancer treatment. These findings support previous studies which have documented the detrimental effects of cancer treatment on women's physical appearance as evidenced by hair loss (Denieffe & Gooney, 2010), skin dryness and changes to the appearance of their finger nails (brittle or discolored). In addition to temporary side-effects of treatment, many women in this sample experienced long-term changes in their physical appearance such as scarring, the loss of one or both breasts, changes in hair re-growth, breast disfigurement, skin problems due to radiotherapy, changes in weight, changes in the appearance of the genitals, and lymphedema. It is possible that the high frequency of cancer-induced changes in appearance reported by women in this study is a reflection of changes in the diagnosis and treatment for breast cancer. In recent years, surgical techniques have often combined with adjuvant treatments (e.g., radiation, chemotherapy, Tamoxifen) which have well-

known late and long-term side-effects (Hwang et al., 2013) that may alter women's appearance during and after treatment. Indeed, women in this sample reported a high frequency of cancer-induced changes in appearance associated with mastectomy plus adjuvant cancer treatments including breast fibrosis, skin problems due to radiotherapy, changes in weight, lymphedema, and chemotherapy-induced changes in the appearance or skin pigmentation of their genitals.

Body image concerns were also common and distressing for many breast cancer survivors in this sample. As predicted, women in the current study reported high levels of body shame and high levels of transparency (concerns about the obviousness of cancer-related changes in their appearance to others). Comparison of these findings with previously published results indicate that body shame and transparency were higher in this sample than results from another sample of breast cancer survivors (Baxter et al., 2006). It is possible that differences in cancer treatment histories between the samples and the aggressiveness of treatment in particular, may partially account for these findings as 60% of women in the current study received a mastectomy compared to 20% of the women from Baxter and colleagues (2006). Higher levels of transparency concerns, and to a lesser extent, body shame, found in this sample of breast cancer survivors could also reflect differences in age between samples as the mean age of participants in this study was 47.3 years compared to 61 years reported by Baxter and colleagues (2006). It is possible that younger women may experience greater concern about how others perceive their body post-treatment than older women diagnosed and treated for breast cancer. Supporting this, previous studies have found significant differences in the prevalence of body image concerns in younger women with breast cancer compared to older survivors, with younger women experiencing greater body image concerns after treatment (Ganz et al., 1998). Examined in a broader context, these findings may also reflect societal definitions of physical beauty which

place greater pressure on younger women, regardless of health status, to achieve an appearance that is often unrealistic and unattainable. Thus, younger survivors may be more invested in maintaining their physical appearance in public, both during and after treatment, compared to older survivors (Baucom, Porter, Kirby, Gremore, & Keefe, 2006). Additionally, younger survivors who compare themselves to unrealistic beauty standards might experience emotional distress and negative perceptions of themselves and their bodies as a result of cancer-related changes in their physical appearance and, in turn, increase their risk for developing persistent body image concerns.

High levels of body image concerns during sexual activity and elevated dysmorphic appearance concern were also found in this sample of breast cancer survivors. Indeed, results from this sample reveal that body image concerns during sexual activity were common among survivors and higher than published means for women of a similar age without a history of cancer (Lowder et al., 2010). Additionally, high levels of dysmorphic appearance concern were reported by women in this study with 26.3% of women scoring above the clinical cut-off (Littleton et al., 2005). Compared to a previous community sample of women, breast cancer survivors in this sample reported moderately higher levels of dysmorphic appearance concerns (Littleton & Breitkopf, 2008). Themes from open-ended qualitative questions appeared consistent with these findings in that a proportion of women described persistent dissatisfaction with their appearance, patterns of avoidance and interference in social activities due to appearance concerns, and making significant changes to their wardrobe to camouflage perceived defects. Taken together, it is clear that diagnosis and treatment for breast cancer potentially has a significant impact on how women perceive changes in their appearance and their bodies after treatment. For a sizable proportion of these women, body image concerns persist and worsen

over time, and in turn, contribute to the development of a psychological disorder. Indeed, not surprisingly, dysmorphic concern was more highly correlated with psychological distress than other study variables examined. Thus, it is possible that persistent dysmorphic concern may be an important contributing factor to the development and maintenance of long-term psychological problems in breast cancer survivors.

In addition to body image concerns, persistent sexual difficulties were reported by the majority of breast cancer survivors in this sample. Only 68% of partnered women in this study reported engaging in sexual activity in the month prior to participation this research; this rate is consistent with rates reported by Meyerowitz and colleagues (1999) and Fobair and colleagues (2006) in similar samples of breast cancer survivors. Among women who were sexually active, high levels of sexual dysfunction and sexual dissatisfaction were reported. Indeed, 69% of sexually active survivors in this sample met criteria for sexual dysfunction based on published clinical cut-offs (Rosen et al., 2000). Thus, only approximately 21% of women in the sample were sexually active and did not have sexual dysfunction. Compared to similar samples of breast cancer survivors, women reported similarly high levels of sexual dysfunction (Ganz et al., 1998; Speer et al., 2005). With regards to sexual dissatisfaction, 59% of sexually active breast cancer survivors reported disappointment and dissatisfaction with their sex life. Similar themes of frustration and sadness associated with sexual problems emerged from women's responses to open-ended questions about perceived changes in sexuality after treatment. Overall, data obtained from self-report measures as well as women's responses to open-ended questions revealed a persistent pattern of post-treatment sexual problems in a large percentage of survivors. Sexual problems were often attributed to poor communication between sexual partners, difficulty

telling their partner what they like and do not like sexually, and disappointment in their own sexual behaviors.

Predictors of sexual dissatisfaction and sexual dysfunction were also examined in this study. Overall, results suggest that sexual adjustment after cancer is not strongly related to socio-demographic factors including relationship status, ethnic background, education and socioeconomic status. However, lack of variance across demographic variables in this sample may have influenced study findings as the majority of women were European American, married, and well-educated. In contrast, medical treatment variables and general distress significantly predicted sexual problems and sexual dissatisfaction. These findings are consistent with those of Ganz and colleagues (1999) and Fobair and colleagues (2006) who found cancer treatment variables and mental health to predict sexual satisfaction and sexual dysfunction in breast cancer survivors. Importantly, body image variables emerged as a predictor of sexual dissatisfaction in the expected direction and are consistent with findings reported by Ganz and colleagues (1999) who found poor body image to be associated with less overall sexual satisfaction in a similar sample of breast cancer survivors. Taken together, results from this study as well as previous research suggest that women who are preoccupied with appearance-based concerns may experience greater disruptions in their sexual relationships which are reflected by less overall satisfaction with their sexual experiences.

Conversely, after demographics, medical treatment variables and general distress variables were entered into the model, body image variables failed to predict sexual dysfunction in this sample of breast cancer survivors. These results are inconsistent with those reported by Fobair and colleagues (2006) who found body image variables to still predict sexual problems after accounting for medical and psychosocial variables. Differences in study findings could

potentially be due to differences in measures used to assess outcomes (body image and sexual dysfunction measures) as well as differences in sample size. Compared to the sample size in this study ($n = 219$), Fobair and colleagues' study involved 546 women, and thus had greater power to detect statistical differences. Thus, it is possible that a larger sample size in this study would have produced results consistent with prior research.

For many survivors, physical changes in appearance due to cancer treatment are associated with increased body image concerns (Falk Dahl et al., 2010) and sexual problems (Denieffe & Gooney, 2010). As an extension of previous research, the current study sought to identify the underlying mechanisms that mediated the relationship between cancer-related changes in appearance and post-treatment sexual dysfunction and sexual dissatisfaction. Results indicate that higher levels of body shame, transparency, and dysmorphic concern, significantly mediated the relationship between a greater number of cancer-related changes in appearance and higher levels of post-treatment sexual dissatisfaction. Body shame and dysmorphic concern also significantly mediated the relationship between a greater number of cancer-related changes in appearance and higher levels of post-treatment sexual dysfunction. Results from these analyses suggest that cancer-related changes in appearance, particularly long-term changes such as scarring, breast changes, weight changes, and changes in hair and skin may lead to the development and persistence of shame about one's body as well as increased appearance monitoring, and in turn, increase survivors' risk for long-term sexual problems.

In contrast, transparency failed to mediate the relationship between a greater number of cancer-related changes in appearance and higher levels of post-treatment sexual dysfunction. It is possible that transparency failed to predict sexual dysfunction because it measures women's concern about the obviousness of cancer to others in (e.g., worrying about one's prosthesis

slipping or others noticing that one's breasts are abnormal) which may be a less relevant psychological construct in the context of a sexual encounter. Qualitative data collected in this study with regards to women's perceptions of their body image after treatment appears to support this discrepancy between survivors' concerns about the transparent nature of cancer-induced changes in appearance in public situations compared to self-evaluations in private. For example, many women described a pattern of taking steps to appear "normal" in public such as having breast reconstruction and their responses revealed less concern about public evaluations of their appearance. However, many of these women described feeling intensely dissatisfied with their bodies and cancer-induced changes in appearance when nude.

Taken together, results from these analyses support the idea that how women perceive themselves and their bodies after diagnosis and treatment for breast cancer directly affects their sexual relationships and post-treatment sexual adjustment. That is, cancer-related changes in appearance may fuel changes in how women perceive their bodies after treatment. In turn, survivors who endorse more negative perceptions of themselves and their bodies may be more likely to develop long-term sexual problems and/or be less satisfied with their sexual experiences. It is also possible that women with greater body image concerns, particularly body shame and dysmorphic concern are more likely to experience somatic hypervigilance or heightened awareness of changes to their body or appearance as a result of cancer. Preoccupation with cancer-related changes in appearance may cause some women to perceive alterations as more substantial than women with less body image concerns who are not highly preoccupied with changes in their appearance.

In addition, prior research in women without a history of breast cancer has shown that body image concerns during sexual activity is a stronger predictor of women's sexual

dysfunction and sexual dissatisfaction than general appearance dissatisfaction (Pujols et al., 2010). As an extension of this work, mediation analyses were conducted to examine body image concerns during sexual activity as a mediator of the relationship between body image concern and post-treatment sexual adjustment. Results supported that body image concerns during sexual activity mediated the relationship between body shame, transparency, and dysmorphic concern and post-treatment sexual dysfunction and sexual dissatisfaction. This pattern is consistent with previous research in women without a history of cancer and supports the possibility that higher levels of general appearance-based concerns may increase survivors' risk for poor sexual adjustment after treatment due to the increased exposure and focus on one's body during sexual activity. For some women, increased body exposure during sex may increase negative thoughts about themselves and their bodies and potentially disrupt a sexual encounter. Not surprisingly, repeated cognitive disruptions during sexual activity may have a detrimental effect on breast cancer survivors' sexual functioning and overall satisfaction with their sexual experiences (Pujols et al., 2010). It is also reasonable to expect heightened body image concerns during sexual activity in breast cancer survivors due to the inherent physical changes to an important erogenous zone on women's bodies as a result of cancer and its treatment. Thus, for survivors who developed strategies to camouflage perceived defects in their daily lives, sexual activity would create a situation where they would be unable implement these strategies, which in turn, may increase their risk for high levels of body image concerns during sex.

Limitations

Several limitations should be noted with regard to the current study. First, results from this study were based on breast cancer survivors' retrospective self-reports of body image concerns and sexual behaviors in the month prior to completing the online survey. It is

acknowledged and routinely reported in the literature that self-report can be influenced by a number of factors such as feelings of self-consciousness related to responses, providing socially desirable responses and memory biases. However, emerging studies on the benefits of web-based research suggest that web-based surveys facilitate the provision of sensitive information from research participants due to perceived increases in confidentiality and anonymity (Ong & Weiss, 2000). Another potential limitation of the current study is the homogenous sample of breast cancer survivors who participated in the research. Although women ranged in age from 22 to 81 years old, participants in the current study were primarily European American, married or cohabitating, well-educated, and had an annual income of $45,000 or more. Homogenous samples of predominately White, middle-class, well-educated women are common in breast cancer research (Pikler & Winterowd, 2003) and consistently limit generalizability of research findings to the broader breast cancer population. Unfortunately efforts to recruit a more diverse sample for the current study were unsuccessful and as a result, findings from the current study may not generalize to the diverse group of women diagnosed and treated for breast cancer. Nonetheless, had a more diverse sample of survivors participated in this research it is possible that ethnic minority women may have reported higher levels of body image acceptance and less body image concerns than White women diagnosed and treated for breast cancer. Indeed, prior research on cultural differences in body image among women without a history of cancer suggest that African American women are more likely to accept their weight, body shape, and appearance than White women (Allan, Mayo, & Michel, 1993). As an extension of this work, futures studies should examine if cultural factors are an important protective factor for ethnic minority women after treatment for breast cancer.

Third, the open-ended question included in the online survey that asked participants to provide their age was not provided by 30.1% (n = 66) of respondents who completed the questionnaire. Given the sensitive nature of topics discussed in this survey, it seems unlikely that participants were uncomfortable providing that type of personal information. A more likely explanation is that the open-ended question format differed from the multiple-choice format used for all other demographic questions on the questionnaire and that women may have simply overlooked that particular question on the online survey. As a result, the extent to which age was related to other study variables could not be evaluated. Fourth, sample characteristics of women who agreed to participate in the current study may also be viewed as a limitation. Given that the research was advertised as a study about body image concerns and sexuality in breast cancer survivors, it is possible that women who currently experienced body image concerns or sexual problems post-treatment may have been more likely to participate in the research.

In addition, the measure used to assess sexual dysfunction in this study may be viewed as a potential limitation due to its focus on specific stages of women's sexual behavior (e.g., desire, arousal, orgasm) and the frequency of overt sexual behaviors (e.g., intercourse). Thus, results from this study were limited to overt sexual behaviors and failed to examine the broad range of sexual activities women may engage in including overt sexual behaviors as well as physically affectionate behaviors (e.g., kissing, hugging, holding hands). Another potential limitation of this research was the overall fairly low levels of psychological distress reported by the study sample. Although longitudinal studies suggest that a majority of breast cancer survivors demonstrate an improvement in psychological functioning over time, a subgroup of women may continue to experience elevated levels of distress for years after treatment (Helgeson, Snyder, & Seltman, 2004). Thus, it is possible that women who were less distressed were more likely to

participate in this study and results may not generalize to women with sustained elevations in psychological distress. Finally, approximately one-third of the data collected in the current study related to sexual dysfunction had to be excluded from analyses due to sexual inactivity in the month prior to participation in this research.

Future Directions

Implications for Research. Despite these limitations, results from the current study have important implications for future research on breast cancer survivors and clinical management of ongoing survivorship concerns. For example, results highlight the need for longitudinal research to improve our understanding and treatment of the long-term effects of cancer and its treatment. Indeed, evidence from women's qualitative responses with regards to body image perceptions after treatment indicate that unpleasant side-effects of treatment currently conceptualized as temporary symptoms, such as changes in weight or skin problems, may persist and adversely affect women's body image for years after treatment. Similarly, qualitative data from this study reveals that women frequently associated persistent changes in appearance with psychological distress, anger, sadness and intense frustration. Taken together, these findings suggest that some appearance changes could be long-term and lead to psychosocial difficulties for women diagnosed and treated for breast cancer. In addition to longitudinal studies, future research should also evaluate which cancer-induced changes in appearance are most distressing for women as well as identify factors that potentially mediate or moderate the relationship between cancer-induced changes in appearance and long-term psychological distress. For example, future research should examine various coping strategies as potential mediators of the relationship between cancer-related changes in appearance and long-term psychological adjustment. Likewise, social support, particularly from a partner or loved

one, may be an important factor that moderates the effects of cancer-induced changes in appearance on women's long-term psychosocial adjustment.

Results from this study also suggest that clinically significant body image concern or dysmorphic appearance concern may be common among breast cancer survivors. Indeed, 26.3% of women in this sample reported clinically significant dysmorphic appearance concern, characterized by intense dissatisfaction and embarrassment regarding the defect, compulsive checking of the defect, attempting to camouflage or hide the defect from others, seeking medical treatment to correct the defect, and avoiding or experiencing interference in social activities due to body image concerns (Littleton et al., 2005). Overall, study findings suggest that dysmorphic appearance concern is a prevalent psychological problem among breast cancer survivors that warrants further attention from researchers. As such, the psychosocial implications of living with clinically significant concerns about a perceived defect or defects in one's appearance needs to be explored in future research investigations. Future investigations should also explore the effects of dysmorphic appearance concern on survivors' psychological health, physical well-being, as well as their interpersonal and sexual relationships. Additionally, research regarding the influence of physical, cultural, and psychosocial factors as it relates to this disorder in breast cancer survivors is warranted. Dysmorphic appearance concern may also be a potentially important factor in women's decision to pursue breast reconstructive surgery or other cosmetic treatment after treatment. For example, previous studies have found that individuals with dysmorphic appearance concerns are more likely to seek medical treatment to correct perceived defects in appearance (Castle, Molton, Hoffman, Preston, & Phillips, 2004). Thus, it is possible that frequent and intense negative thoughts about themselves and their bodies may fuel survivors' decision to pursue reconstructive surgery or other cosmetic treatments. Importantly,

dysmorphic concern may also explain why a sizable percentage of women who receive reconstructive surgery continue to experience severe body image concerns after surgery. Clearly, additional research is needed to better understand the relationship between dysmorphic appearance concern and survivors' decisions to pursue breast reconstruction or other medical interventions after treatment, as well as evaluate the effects of reconstructive surgery and other treatments on women's body image, quality of life, and interpersonal relationships.

Consistent with published research, results from the current study indicate that a majority of breast cancer survivors experience sexual problems and sexual dissatisfaction after treatment. While a number of individual factors that likely contributed to sexual difficulties in cancer survivors were examined, interpersonal and partner-relationship variables, such as communication with regards to sexual preferences or problems, were not directly assessed in this study. It is acknowledged that a partner's sexual problems or relationship difficulties could adversely affect a woman's sexual experiences and satisfaction with a sexual relationship. While these themes were not directly examined in this research, they were consistently reported by women who responded to open-ended questions about changes in their sexuality after breast cancer. As an extension of this study, future research should examine how these individual factors interact with partner-relationship factors in the context of body image, sexuality and cancer survivorship.

Another important area for future research would be to examine cultural differences as they relates to body image concerns and sexual dysfunction in breast cancer survivors. Results from the current study describe survivorship concerns in a homogenous sample of White, well-educated women. However, it remains unclear if specific cancer-related changes in appearance, body image concerns, and sexual difficulties are present or how they affect women of various

racial, ethnic, socioeconomic and educational backgrounds. Future research is needed to examine cancer-related changes in appearance among women of diverse demographic backgrounds. Identification of these differences could, in turn, facilitate the development of targeted behavioral and psychological interventions designed to address the unique needs of a diverse population of breast cancer survivors.

Finally, results from the current study suggest that multiple factors play a role in shaping women's body image and sexual adjustment after diagnosis and treatment for breast cancer. While this study identified a number of psychological factors that affect how women perceive themselves and their bodies, and in turn, influence their sexual relationships, further research is needed to establish the reliability of these findings. Additionally, the current study focused on the relationship between cognitive perceptions of women's bodies and their sexual functioning and satisfaction. As an extension of this research, future studies should examine how these distorted cognitions affect women's sexual behaviors. For example, research should examine the effects of elevated body image concerns on women's decision to initiate sexual activity, as well as consent to sexual activity initiated by their partner. Future studies should also examine the effects of body image concerns on a broad range of sexual behaviors, including overt sexual acts as well as physically affectionate behaviors.

Implications for Clinical Practice. In addition to advancing research on body image concerns and sexual problems in breast cancer survivors, results from this study underscore the need for psycho-education, routine assessment, and clinical management of these sequelae in oncology clinics. It seems clear that women and their partners would benefit from discussions with medical professionals about potential changes in appearance and sexual problems that may occur during and after treatment for breast cancer. In the current study, a majority of women

reported that they felt unprepared and lacked knowledge about potential appearance changes or sexual difficulties they may experience as a result of treatment. For a sub-group of women in this sample, insufficient knowledge about the long-term effects of treatment was associated with strong feelings of shame and self-blame, which one participant characterized as "feeling like a survivor but not a woman." Not surprisingly, negative emotions about themselves and their bodies were associated with sexual problems and sexual relationship difficulties among women in this study. Future psycho-educational programs should educate women and their partners about the late and long-term sexual side-effects of treatment and potential cancer-related changes in appearance, normalize these concerns among cancer survivors, as well as provide referrals to mental health professionals for women who struggle with body image concerns and sexual problems after treatment. Providers should also continuously assess for body image concerns and sexual problems during and after cancer treatment. Referrals should be made to appropriate mental health providers or patient support groups, if indicated. In addition to facilitating mental health referrals, routine assessment for clinically significant body image concern in oncology clinics may help providers identify women with dysmorphic appearance concerns who are interested in reconstruction surgery but have a high risk for adverse outcomes. It is possible that these women may benefit from a pre-surgical psychological intervention designed to target distorted appearance concerns and maladaptive behaviors as a pre-requisite for surgical intervention.

Finally, this study underscores the need for empirically-supported interventions for women who experience clinically significant body image concerns and sexual problems after diagnosis and treatment for breast cancer. For example, women who experience ongoing distress would likely benefit from a cognitive-behavioral intervention designed to provide patient

education related to post-treatment body image concerns and sexual problems, discuss strategies to modify cognitions and behaviors that contribute to the maintenance and exacerbation of body image concerns and sexual problems, as well as teach relaxation skills and effective communication strategies. Indeed, results from this study suggest that distorted thoughts, particularly during sexual activity, were common and could potentially be addressed with cognitive restructuring techniques in future interventions. Likewise, women may also benefit from instruction in anxiety management skills, such as relaxation training or mindfulness techniques, that may enhance survivor's ability to cope with acute and long-term survivorship concerns as well as general life stressors. Additionally, results from this study suggest that sexual problems are often undiagnosed and untreated. Therefore, women may benefit from a brief intervention focused on strategies for effective communication with healthcare providers. It is possible that this type of intervention may empower women to initiate discussions with their treatment team about important quality of life issues, including body image concerns and sexual problems.

Partnered women may also benefit from a couples-based intervention, as evidence from the current study identified partner-relational factors as a key contributing factor to both positive and negative post-treatment sexual outcomes. A couples-based cognitive-behavioral intervention should aim to provide education about long-term survivorship concerns and facilitate discussions between partners with regards to potential changes in their sexual relationship after cancer. Patterns of problematic thinking such as body image concerns during sex should also be addressed. Further, current patterns of communication should be examined and strategies for more effective communication between partners should be included (e.g., speaker-listener technique), if indicated.

In addition to individual and couples-based treatments, results from this study clearly demonstrate a need for psychological interventions for women with dysmorphic appearance concerns who are interested in pursuing reconstructive surgery as the have a greater risk for persistent or worsening body image concerns after corrective surgery. For example, future interventions could be developed from existing cognitive-behavioral models used in the treatment of body dysmorphic disorder (BDD) due to their similar symptomatology and patterns of maladaptive cognitions and behaviors. Thus, it is possible that evidence-based treatments for BDD (e.g., exposure-based cognitive-behavioral interventions) may also reduce symptoms of dysmorphic concern in breast cancer survivors. Further, this type of pre-surgical intervention may provide women with a more realistic perspective of their likely surgical outcomes as well address underlying psychological and behavioral symptoms that perpetuate body image concerns and increase women's risk for adverse post-surgical outcomes.

In sum, this study reveals that for many breast cancer survivors, successful management of the disease is often associated with long-term body image concerns and sexual difficulties that potentially interfere with women's psychological well-being and interpersonal relationships after treatment. Further, this study highlights the need for further research, routine assessment and clinical management of these sequelae in oncology clinics. Research and intervention in these areas will improve our understanding of the experiences of women diagnosed and treated for breast cancer as well as more effectively assist women in their physical, emotional, and interpersonal recovery.

References

American Cancer Society (2008). *Cancer facts and figures 2008*. Retrieved January 20, 2011, from http://www.cancer.org/downloads/STT/2008CAFFfinalsecured.pdf

Anagnostopoulos, F., & Myrgianni, S. (2009). Body image of Greek breast cancer patients treated with mastectomy or breast conserving surgery. *Journal of Clinical Psychology in Medical Settings*, *16*, 311-321. doi: 10.1007/s10880-009-9176-5

Archibald, S., Lemieux, S., Byers, E. S., Tamlyn, K., & Worth, J. (2006). Chemically-induced menopause and the sexual functioning of breast cancer survivors. *Women & Therapy, 29*, 83-106. doi: 10.1300/J015v29n01_05

Barni, S., & Mondin, R. (1997). Sexual dysfunction in treated breast cancer patients. *Annals of Oncology, 8*, 149-153.

Baron, R.M., & Kenny, D.A. (1986). The moderator–mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, *51*, 1173-1182. doi: 10.1037//0022-3514.51.6.1173

Baser, R. E., Li, Y., & Carter, J. (2012). Psychometric validation of the Female Sexual Function Index (FSFI) in cancer survivors. *Cancer*, *118*, 4606-4618. doi: 10.1002/cncr.26739

Basson, R. (2010). Sexual function of women with chronic illness and cancer. *Women's Health, 6*, 407-429. doi:10.2217/whe.10.23

Baucom, D. H., Porter, L. S., Kirby, J. S., Gremore, T. M., & Keefe, F. J. (2006). Psychosocial issues confronting young women with breast cancer. *Breast Disease*, *23*, 103-113.

Baxter, N. N., Goodwin, P. J., McLeod, R. S., Dion, R., Devins, G., & Bombardier, C. (2006). Reliability and validity of the Body Image after Breast Cancer Questionnaire. *The Breast Journal, 12*, 221-232. doi: 10.1111/j.1075-122X.2006.00246.x

Bower, J. E., Ganz, P. A., Desmond, K. A., Rowland, J. H., Meyerowitz, B. E., & Belin, T. R. (2000). Fatigue in breast cancer survivors: Occurrence, correlates, and impact on quality of life. *Journal of Clinical Oncology, 18,* 743-753.

Brady, M.J., Cella D.F., Mo, F., Bonomi, A.E., Tulsky, D.S., Lloyd, S.R., Deasy, S., Cobleigh M., & Shiomoto, G. (1997). Reliability and validity of the Functional Assessment of Cancer Therapy-Breast (FACT-B) quality of life instrument. *Journal of Clinical Oncology,* 15, 974-986.

Brown, T. A., Chorpita, B. F., Korotitsch, W., & Barlow, D. H. (1997). Psychometric properties of the Depression Anxiety Stress Scales (DASS) in clinical samples. *Behaviour research and therapy, 35*(1), 79-89. doi: 10.1016/S0005-7967(96)00068

Carelle, N., Piotto, E., Bellanger, A., Germanaud, J., Thuillier, A., & Khayat, D. (2002). Changing patient perceptions of the side effects of cancer chemotherapy. *Cancer, 95*, 155-163. doi: 10.1002/cncr.10630

Carver, C. S., Smith, R. G., Antoni, M. H., Petronis, V. M., Weiss, S., & Derhagopian, R. P. (2005). Optimistic personality and psychosocial well-being during treatment predict psychosocial well-being among long-term survivors of breast cancer. *Health Psychology, 24*, 508-516.doi: 10.1037/0278-6133.24.5.508

Cash, T.F. (2004). *Body-image assessments: Manuals and questionnaires.* Unpublished manuscript. Norfolk, VA.

Cash, T. F., Maikkula, C. L, & Yamamiya, Y. (2004). "Baring the body in the bedroom": Body image, sexual self schemas, and sexual functioning among college women and men. *Electronic Journal of Human Sexuality,* 7. Retrieved December 22, 2010 from http://www.ejhs.org/volume7/bodyimage.html.

Cash, T. F, & Pruzinsky, T. (Eds.). (1990). *Body images: Development, deviance, and change.* New York: Guilford.

Castle, D. J., Molton, M., Hoffman, K., Preston, N. J. & Phillips, K. A. (2004). Correlates of dysmorphic concern in people seeking cosmetic enhancement. *Australian and New Zealand Journal of Psychiatry, 38*, 439-444. doi: 10.1111/j.1440-1614.2004.01381.x

Deimling, G. T., Bowman, K. F., Sterns, S., Wagner, L. J., & Kahana, B. (2006). Cancer-related health worries and psychological distress among older adult, long-term cancer survivors. *Psycho-Oncology, 15*, 306–320. doi: 10.1002/pon.955

Denieffe, S., & Gooney, M. (2010). A meta-synthesis of women's symptoms experience and breast cancer. *European Journal of Cancer Care, 20*, 424-435. doi: 10.1111/j.1365-2354.2010.01223.x.

Dizon, D. S. (2009). Quality of life after breast cancer: Survivorship and sexuality. *The Breast Journal, 15*, 500-504. doi: 10.1111/j.1524-4741.2009.00766.x

Dow, K. H., Ferrell, B. R., Leigh, S., Ly, J., & Gulasekaram, P. (1996). An evaluation of the quality of life among long-term survivors of breast cancer. *Breast Cancer Research and Treatment, 39*, 261-273. doi: 10.1007/bf01806154

Edwards, J. R., & Lambert, L. S. (2007). Methods for integrating moderation and mediation: A general analytical framework using moderated path analysis. *Psychological Methods, 12,* 1-22. doi:10.1037/1082-989X.12.1.1

Falk Dahl, C. A., Reinertsen, K. V., Nesvold, I. L., Fossa, S. D., & Dahl, A. A. (2010). A study of body image in long-term breast cancer survivors. *Cancer, 116*, 3549-3557. doi:10.1002/cncr.25251

Flynn, K. E., Jeffery, D. D., Keefe, F. J., Porter, L. S., Shelby, R. A., Fawzy, M. R., Gosselin, T. K., Reeve, B. B., & Weinfurt, K. P. (2010). Sexual functioning along the cancer continuum: Focus group results from the Patient-Reported Outcomes Measurement Information System (PROMIS®). *Psycho-Oncology*. doi: 10.1002/pon.1738

Fobair, P., Stewart, S. L., Chang, S., D'Onofrio, C., Banks, P. J., & Bloom, J. R. (2006). Body image and sexual problems in young women with breast cancer. *Psycho-Oncology, 15*, 579-594. doi: 10.1002/pon.991

Fobair, P., & Spiegel, D. (2009). Concerns about sexuality after breast cancer. *The Cancer Journal, 15*, 19-26. doi: 10.1097/PPO.1090b1013e31819587bb

Freedman, T. G. (1994). Social and cultural dimensions of hair loss in women treated for breast cancer. *Cancer Nursing, 17*, 334-341. doi: 10.1097/00002820-199408000-00006

Fritz, M. S., & MacKinnon, D. P. (2007). Required sample size to detect the mediated effect. *Psychological Science, 18*, 233–239. doi: 10.1111/j.1467-9280.2007.01882.x

Gallagher, P., Buckmaster, A., O'Carroll, S., Kiernan, G., & Geraghty, J. (2009). Experiences in the provision, fitting and supply of external breast prostheses: Findings from a national survey. *European Journal of Cancer Care, 18*, 556-568. doi: 10.1111/j.1365-2354.2007.00898.x

Ganz, P. A., Coscarelli, A., Fred, C., Kahn, B., Polinsky, M. L., & Petersen, L. (1996). Breast cancer survivors: Psychosocial concerns and quality of life. *Breast Cancer Research and Treatment, 38*, 183-199. doi: 10.1007/bf01806673

Ganz, P. A., Desmond, K. A., Belin, T. R., Meyerowitz, B. E., & Rowland, J. H. (1999). Predictors of sexual health in women after a breast cancer diagnosis. *Journal of Clinical Oncology, 17*, 2371-2380.

Ganz, P. A., Desmond, K. A., Leedham, B., Rowland, J. H., Meyerowitz, B. E., & Belin, T. R. (2002). Quality of life in long-term, disease-free survivors of breast cancer: A follow-up study. *Journal of the National Cancer Institute, 94*, 39-49. doi: 10.1093/jnci/94.1.39

Ganz, P. A., Rowland, J. H., Desmond, K., Meyerowitz, B. E., & Wyatt, G. E. (1998). Life after breast cancer: understanding women's health-related quality of life and sexual functioning. *Journal of Clinical Oncology,* 16(2), 501-514.

Gerard, D. (1982). Sexual functioning after mastectomy: Life vs. lab. *Journal of Sex & Marital Therapy, 8*, 305-315. doi: /10.1080/00926238208405436

Gloster, A. T., Rhoades, H. M., Novy, D., Klotsche, J., Senior, A., Kunik, M., Wilson, N., & Stanley, M.A. (2008). Psychometric properties of the Depression Anxiety and Stress Scale-21 in older primary care patients. *Journal of Affective Disorders, 110*, 248-259.

Goodwin, P. J., Ennis, M., Pritchard, K. I., McCready, D., Koo, J., Sidlofsky, S., Trudeau, M., Hood, N., & Redwood, S. (1999). Adjuvant treatment and onset of menopause predict weight gain after breast cancer diagnosis. *Journal of Clinical Oncology, 17*, 120-129.

Hangen, J.D., & Cash, T.F. (1991). The relationships of body-image attitudes to sexual functioning and experiences in a normal college population. *Dissertation Abstracts International, 52*, 1061.

Harcourt, D., & Frith, H. (2008).Women's experiences of an altered appearance during chemotherapy. *Journal of Health Psychology, 13*, 597-606. doi: 10.1177/1359105308090932

Helgeson, V. S., Snyder, P., & Seltman, H. (2004). Psychological and physical adjustment to breast cancer over 4 years: Identifying distinct trajectories of change. *Health Psychology, 23*, 3-15. doi: 10.1037/0278-6133.23.1.3.

Helms, R. L., O'Hea, E. L., & Corso, M. (2008). Body image issues in women with breast cancer. *Psychology, Health & Medicine, 13,* 313-325. doi: 10.1080/13548500701405509

Henry, J. D., & Crawford, J. R. (2005). The short-form version of the Depression Anxiety Stress Scales (DASS-21): Construct validity and normative data in a large non-clinical sample. *British Journal of Clinical Psychology, 44,* 227–239. doi:10.1348/014466505X29657

Holmes, W., Clemmens, D., & Froman, R. (2000). The Female Sexuality Questionnaire: Instrument development. *Journal of Nursing Measurement, 8,* 87-99.

Hormes, J. M., Lytle, L. A., Gross, C. R., Ahmed, R. L., Troxel, A. B., & Schmitz, K. H. (2008). The Body Image and Relationships Scale: Development and validation of a measure of body image in female breast cancer survivors. *Journal of Clinical Oncology, 26,* 1269-1274. doi: 10.1200/jco.2007.14.2661

Hunt K. K., Robb, G. L., Strom, E. A., & Ueno, N. T. (Eds). (2007). *Breast Cancer. MD Anderson Cancer Care Series*. New York: Springer.

Hwang, E. S., Lichtensztajn, D. Y., Gomez, S. L., Fowble, B., & Clarke, C. A. (2013). Survival after lumpectomy and mastectomy for early stage invasive breast cancer. Advance online publication. doi: 10.1002/cncr.27795

Kissane, D., White, K., Cooper, K., & Vitetta, L. (2004) Psychosocial impact in the areas of body image and sexuality for women with breast cancer. Camperdown, Australia: National Breast Cancer Centre

Kornblith, A. B., Herndon, J. E., Weiss, R. B., Zhang, C., Zuckerman, E. L., Rosenberg, S., Mertz, M., Payne, D., Jane Massie, M., Holland, J. F., Wingate, P., Norton, L., & Holland, J. C. (2003). Long-term adjustment of survivors of early-stage breast carcinoma, 20 years after adjuvant chemotherapy. *Cancer, 98,* 679-689. doi: 10.1002/cncr.11531

Lam, W. W. T., & Fielding, R. (2003). The evolving experience of illness for Chinese women with breast cancer: A qualitative study. *Psycho-Oncology, 12*, 127-140. doi: 10.1002/pon.621

Lambrou, C., Veale, D., & Wilson, G. (2012). Appearance concerns comparisons among persons with body dysmorphic disorder and nonclinical controls with and without aesthetic training. *Body Image, 9*, 86-92.

Lindley, C., Vasa, S., Sawyer, W. T., & Winer, E. P. (1998). Quality of life and preferences for treatment following systemic adjuvant therapy for early-stage breast cancer. *Journal of Clinical Oncology, 16*, 1380-1387.

Littleton, H. L., Axsom, D., & Pury, C. L. S. (2005). Development of the Body Image Concern Inventory. *Behaviour Research and Therapy, 43*, 229-241. doi: 10.1016/j.brat.2003.12.006

Littleton, H., & Breitkopf, C. R. (2008). The Body Image Concern Inventory: Validation in a multiethnic sample and initial development of a Spanish language version. *Body Image, 5*, 381-388. doi: 10.1016/j.bodyim.2008.06.004

Lovibond, S. H., & Lovibond, P.F. (1995). *Manual for the Depression Anxiety Stress Scales*. (2nd. Ed.) Sydney: Psychology Foundation.

Lowder J, L., Ghetti, C., Moalli, P., Zyczynski, H., & Cash T, F. (2010). Body image in women before and after reconstructive surgery for pelvic organ prolapse. *International Urogynecology Journal, 21*, 919-25. doi: 10.1007/s00192-010-1141-1

Meyerowitz, B. E., Desmond, K. A., Rowland, J. H., Wyatt, G. E., & Ganz, P. A. (1999). Sexuality following breast cancer. *Journal of Sex & Marital Therapy, 25*, 237–250. doi: 10.1080/00926239908403998

Moreira, H., Silva, S., & Canavarro, M. C. (2010). The role of appearance investment in the adjustment of women with breast cancer. *Psycho-Oncology, 19,* 959-966. doi: 10.1002/pon.1647

Morrell, R. M., Halyard, M. Y., Schild, S. E., Ali, M. S., Gunderson, L. L., & Pockaj, B. A. (2005). Breast cancer-related lymphedema. *Mayo Clinic Proceedings, 80,* 1480-1484. doi: 10.4065/80.11.1480

Mourits, M. J., Bockermann, I., de Vries, E. G., van der Zee, A. G., ten Hoor, K. A., van der Graaf, W., Sluiter, W., & Willemse, P. (2002). Tamoxifen effects on subjective and psychosexual well-being, in a randomized breast cancer study comparing high-dose and standard-dose chemotherapy. *British Journal of Cancer, 86,* 1546-1550. doi:10.1038/sj.bjc.6600294

Muthén, L., & Muthén, B. (1998-2007). Mplus user's guide [Computer software]. Los Angeles, CA: Muthén & Muthén.

Münstedt, K., Manthey, N., Sachsse, S., & Vahrson, H. (1997). Changes in self-concept and body image during alopecia induced cancer chemotherapy. *Supportive Care in Cancer, 5,* 139-143. doi: 10.1007/bf01262572

Ogden, J., & Lindridge, L. (2008). The impact of breast scarring on perceptions of attractiveness. *Journal of Health Psychology, 13,* 303-310. doi: 10.1177/1359105307088132

Ong, A. D., & Weiss, D. J. (2000). The impact of anonymity on responses to sensitive questions. *Journal of Applied Social Psychology, 30,* 1691-1708.

Paskett, E. D., Naughton, M. J., McCoy, T. P., Case, L. D., & Abbott, J. M. (2007). The epidemiology of arm and hand swelling in premenopausal breast cancer survivors.

Cancer Epidemiology Biomarkers & Prevention, 16, 775-782. doi:10.1158/1055-9965.epi-06-0168

Phillips, K. A., McElroy, S. L., Keck, P. E., Pope, H. G., & Hudson, J. I. (1993). Body dysmorphic disorder: 30 cases of imagined ugliness. *American Journal of Psychiatry, 150*, 302–308.

Pikler, V., & Winterowd, C. (2003). Racial and body image differences in coping for women diagnosed with breast cancer. *Health Psychology, 22*, 632-637. doi: 10.1007/s11764-009-0097-y

Preacher, K. J., & Hayes, A. (2004). SPSS and SAS procedures for estimating indirect effects in simple mediation models. *Behavior Research Methods, Instruments, & Computers, 36,* 717-731. doi:10.3758/BF03206553

Pujols, Y., Meston, C. M., & Seal, B. N. (2010). The association between sexual satisfaction and body image in women. *Journal of Sexual Medicine, 7*, 905-916. doi: 10.1111/j.1743-6109.2009.01604.x

Reaby, L. L. (1998). The quality and coping patterns of women's decision-making regarding breast cancer surgery. *Psycho-Oncology, 7*, 252-262.doi: 10.1002/(sici)1099-1611

Ridner, S. H. (2009). The psycho-social impact of lymphedema. *Lymphatic Research and Biology, 7*, 109-112. doi:10.1089/lrb.2009.0004

Rosen, J. C., & Ramirez, E. (1998). A comparison ofeating disorders and body dysmorphic disorder on body image and psychological adjustment. *Journal of Psychosomatic Research, 44*, 441-449.

Rosen, R. C., Brown, C., Heiman, J., Leiblum, S., Meston, C. M., Shabsigh, R., Ferguson, D., & D'Agostino, R. (2000). The Female Sexual Function Index (FSFI): A multidimensional

self-report instrument for the assessment of female sexual function. *Journal of Sex & Marital Therapy, 26,* 191-208.

Rowland, J. H., Desmond, K. A., Meyerowitz, B. E., Belin, T. R., Wyatt, G. E., & Ganz, P. A. (2000). Role of breast reconstructive surgery in physical and emotional outcomes among breast cancer survivors. *Journal of the National Cancer Institute, 92*, 1422-1429. doi:10.1093/jnci/92.17.1422

Schover, L. R., Yetman, R. J., Tuason, L. J., Meisler, E., Esselstyn, C. B., Hermann, R. E., Grundfest-Broniatowski, S., & Dowden, R.V. (1995). Partial mastectomy and breast reconstruction. A comparison of their effects on psychosocial adjustment, body image, and sexuality. *Cancer, 75*, 54-64. doi: 10.1002/1097-0142(19950101)75:1

Speer, J. J., Hillenberg, B., Sugrue, D. P., Blacker, C., Kresge, C. L., Decker, V. B., Zakalik, D., & Decker, D. A. (2005). Study of sexual functioning determinants in breast cancer survivors. *The Breast Journal, 11*, 440-447. doi: 10.1111/j.1075-122X.2005.00131.x

Steginga, S., Occhipinti, S., Wilson, K.,& Dunn, J. (1998). Domains of distress: The experience of breast cancer in Australia. *Oncology Nursing Forum, 25*. Retrieved from http://www.biomedsearch.com/nih/Domains-distress-experience-breast-cancer/9679264.html

Taylor, S. E., Lichtman, R. R., Wood, J. V., Bluming, A. Z., Dosik, G. M., & Leibowitz, R. L. (1985). Illness-related and treatment-related factors in psychological adjustment to breast cancer. *Cancer, 55*, 2506-2513. doi:10.1002/1097-0142

Thomas-MacLean, R. (2005). Beyond dichotomies of health and illness: Life after breast cancer. *Nursing Inquiry, 12*, 200-209. doi: 10.1111/j.1440-1800.2005.00268.x

Van Esch, L., Roukema, J., Van der Steeg, A., & De Vries, J. (2011). Trait anxiety predicts disease-specific health status in early-stage breast cancer patients. *Quality of Life Research*. Advance online publication. doi: 10.1007/s11136-010-9830-2

White, C. A. (2000). Body image dimensions and cancer: A heuristic cognitive behavioral model. *Psycho-Oncology, 9*, 183-192. doi: 10.1002/1099-1611(200005/06)9

Wiederman, M. W. (1996). Women, sex, and food: A review of research on eating disorders and sexuality. *Journal of Sex Research, 33*, 301-311. doi: 10.1080/00224499609551847

Wilmoth, M. C. (2001). The aftermath of breast cancer: An altered sexual self. *Cancer Nursing, 24*, 278-286. doi: 10.1097/00002820-200108000-00006

Wimberly, S. R., Carver, C. S., Laurenceau, J.P., Harris, S. D., & Antoni, M. H. (2005). Perceived partner reactions to diagnosis and treatment of breast cancer: Impact on psychosocial and psychosexual adjustment. *Journal of Consulting and Clinical Psychology, 73*, 300-311. doi: 10.1037/0022-006x.73.2.300

Yang, H. C., & Schuler, T. A. (2009). Marital quality and survivorship. *Cancer, 115*, 217-228. doi: 10.1002/cncr.23964

Yurek, D., Farrar, W., & Andersen, B. L. (2000). Breast cancer surgery: Comparing surgical groups and determining individual differences in postoperative sexuality and body change stress. *Journal of Consulting and Clinical Psychology, 68*, 697-709. doi: 10.1037/0022-006x.68.4.697

Zimmermann, T., Scott, J. L., & Heinrichs, N. (2010). Individual and dyadic predictors of body image in women with breast cancer. *Psycho-Oncology, 19*, 1061-1068. doi: 10.1002/pon.1660

Appendix A
IRB Approval Letter

EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board Office
1L-09 Brody Medical Sciences Building· Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** · Fax **252-744-2284** · **www.ecu.edu/irb**

Notification of Approval (Committee)

From: Social/Behavioral IRB

To: Lindsey Rosman

CC: Heather Littleton

Date: 11/22/2011

Re: UMCIRB 11-001117

Body Image and Sexual Functioning in Breast Cancer Survivors

I am pleased to inform you that at the convened meeting on 11/16/2011 of Social/Behavioral IRB , the committee voted to approve the above study. Approval of the study and the consent form(s) is for the period of 11/16/2011 to 11/15/2012.
The Social/Behavioral IRB deemed this study Minimal Risk.

Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The investigator must adhere to all reporting requirements for this study.

The approval includes the following items:

Name	Description	Modified	Version
AD for online posting.docx	Recruitment Documents/Scripts	11/3/2011 10:49 AM	0.02
consent forms.docx	Consent Forms	11/7/2011 11:39 AM	0.02
LAR Thesis Proposal (Final).docx	Study Protocol or Grant Application	11/7/2011 12:04 PM	0.02
Protocol for Body Image and Sexual Functioning in Breast Cancer Survivors.doc	Study Protocol or Grant Application	10/22/2011 2:28 PM	0.01
research materials.docx |	Surveys and Questionnaires	11/7/2011 11:56 AM	0.05
Sample Email Invitation for Online Survey.docx |	Recruitment Documents/Scripts	10/22/2011 2:35 PM	0.01

The following UMCIRB members were recused for reasons of potential for Conflict of Interest on this research study: S. McCammon. The following UMCIRB members with a potential Conflict of Interest did not attend this IRB meeting: None.

Appendix B
Study Questionnaire

Demographics

How old are you? ____ years

What is your racial or ethnic background? *(check all that apply)*

- White (Caucasian/ European American)
- Caribbean Islander
- Asian or Pacific Islander
- Native American/ Alaskan Native
- Latina or Latin American
- Black or African American
- Multi-ethnic
- Other _____

What is your estimated household income per year (this includes all money made by everyone you live with)?

- Less than $20,000
- $20,100-45,000
- $45,100-60,000
- $60,100-85,000
- $85,100-100,000
- $100,100-150,000
- $150,100-200,000
- Over $200,100

Are you currently in a relationship with a partner or significant other?

- Yes
- No

Relationship Status:

- Single
- Married
- Cohabitating (not married)
- Dating
- Long-term relationship (not cohabitating)
- Separated
- Divorced
- Widowed

□Other _____

How would you describe yourself?

□Heterosexual
□Mostly heterosexual
□Bisexual
□Mostly homosexual
□Homosexual
□Questioning
□Other _____

What is the highest level of education you have completed? *(check one)*

□ Less than high school graduate
□ High school graduate or GED
□ Some college or technical school
□ College graduate
□ Graduate or professional school

Cancer Treatment History

What stage was/were your tumor/s? *(check one)*

□ Stage I- the tumor is 0-2cm and N-0 (no nodes)

□ Stage IIA - either a small tumor with positive lymph nodes or a tumor 2-5cm with negative lymph nodes

□Stage IIB – a tumor 2-5cm with positive lymph nodes or a tumor larger than 5cm with negative lymph nodes

□Stage III – a large tumor with positive lymph node; also referred to as locally advanced

□Stage IIIB – a tumor of any size that has spread to the skin, chest wall, or internal mammary lymph nodes

□Stage IIIC – a tumor of any size that has spread to nodes near the collarbone or to both internal and axillary nodes

□Stage IV – a tumor of any size that has metastasized (spread) to a different site

How were you initially treated? Please mark all that apply:

□ Lumpectomy □Left breast □Right breast □Both breasts

□ Mastectomy without breast reconstruction □Left breast □Right breast □Both breasts

□ Mastectomy with breast reconstruction □Left breast □Right breast □Both breasts

□ Radiation □Left breast □Right breast □Both breasts

□ Chemotherapy

□ Removal of ovaries

□Other _____

Menstrual status *(check one)*

- □ Still menstruating
- □ Stopped menstruating, natural menopause
- □ Stopped menstruating, medical or surgical menopause that is the result of chemotherapy or ovary removal
- □Other _____

Hormone Therapy History (Arimidex, Tamoxifen, Aromasin, FaslodexFemara, Evista, or Fareston):

- □ Currently receiving Hormone Therapy
- □ Received Hormone Therapy in the past
- □ Never received Hormone Therapy

Time since diagnosis (years):

- □ Less than 1 year
- □ 1 year
- □ 2-3 years
- □ 4-5 years
- □ 6 years or more

Sexual Satisfaction

Female Sexuality Questionnaire-Satisfaction Subscale:

Instructions: The items below are a list of statements describing aspects of female sexuality. Please rate each item on the 1 to 5 scale according to how close the statement matches your current feelings. There are no right or wrong answers.

	Strongly Disagree					Strongly Agree
I am satisfied with my sex life.	0	1	2	3	4	5
Something is lacking in my sex life.	0	1	2	3	4	5
My desire to touch and hold is being satisfied.	0	1	2	3	4	5
My love life is disappointing to me.	0	1	2	3	4	5
I am happy with my sexual behavior.	0	1	2	3	4	5
Sex is fun for my partner and myself.	0	1	2	3	4	5
I find it easy to tell my partner what I like and don't like sexually.	0	1	2	3	4	5
I feel disappointed when I think about my sexual experiences.	0	1	2	3	4	5
I am embarrassed to talk about what pleases me with my partner.	0	1	2	3	4	5

Changes in Appearance Related to Cancer Treatment

Instructions: The statements below concern possible changes to your appearance as a result of your diagnosis and treatment for breast cancer. Please indicate whether or not you have experienced any of these changes to your physical appearance:

I experienced hair loss ☐Yes ☐No

My new hair is different (thinner, color, texture) than my old hair ☐Yes ☐No

I experienced changes to my finger nails (brittle, discolored) ☐Yes ☐No

I experienced a change in weight (gain or loss) ☐Yes ☐No

I experienced skin dryness as a result of treatment for breast cancer ☐Yes ☐No

I experienced a change in the appearance or skin pigmentation of my genitals as a result of treatment for breast cancer ☐Yes ☐No

I experienced changes in the size, shape, or color of my nipple and/or areola as a result of treatment for breast cancer or related breast reconstruction ☐Yes ☐No

I experienced lymphedema (swelling caused by fluid accumulation in the limbs) ☐Yes ☐No

I experienced scarring as a result of treatment for breast cancer ☐Yes ☐No

I experienced changes to my skin <u>in the area treated</u> for breast cancer ☐Yes ☐No

If yes, check all that apply:

☐Radiation burn, rash, teleangiectasies (a small patch of tiny blood vessels on the skin of the radiated breast area that look like a tangle of thin red lines)

☐Skin dyspigmentation (skin lightening or darkening)

☐Fibrosis (skin hardening or thickening as a result of radiation treatment)

DASS21

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time any statement.

The rating scale is as follows:

0 Did not apply to me at all

1 Applied to me to some degree, or some of the time

2 Applied to me to a considerable degree, or a good part of time

3 Applied to me very much, or most of the time

I found it hard to wind down	0	1	2	3
I was aware of dryness of my mouth	0	1	2	3
I couldn't seem to experience any positive feeling at all	0	1	2	3
I experienced breathing difficulty (e.g., excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
I found it difficult to work up the initiative to do things	0	1	2	3
I tended to over-react to situations	0	1	2	3
I experienced trembling (e.g., in the hands)	0	1	2	3
I felt that I was using a lot of nervous energy	0	1	2	3
I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
I felt that I had nothing to look forward to	0	1	2	3
I found myself getting agitated	0	1	2	3
I found it difficult to relax	0	1	2	3
I felt down-hearted and blue	0	1	2	3
I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
I felt I was close to panic	0	1	2	3

I was unable to become enthusiastic about anything	0	1	2	3
I felt I wasn't worth much as a person	0	1	2	3
I felt that I was rather touchy	0	1	2	3
I was aware of the action of my heart in the absence of physical exertion (e.g., sense of heart rate increase, heart missing a beat)	0	1	2	3
I felt scared without any good reason	0	1	2	3
I felt that life was meaningless	0	1	2	3

BIBCQ

Instructions: The following pages contain statements about how people might think, feel, or behave after developing breast cancer. You are asked to indicate the way each statement pertains to you personally over the past month.

Please read each statement carefully and decide how it applies to you. Use the following scale to respond to each statement:

1 = Strongly Disagree
2 = Disagree
3 = Neither Disagree nor Agree
4 = Agree
5 = Strongly Agree

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I try to hide my body	1	2	3	4	5
I avoid looking at my scars from breast surgery	1	2	3	4	5
I feel less feminine since cancer	1	2	3	4	5
I would feel comfortable changing in a public change-room	1	2	3	4	5
I feel that part of me must remain hidden	1	2	3	4	5
I am afraid of touching the scars from breast surgery	1	2	3	4	5
I avoid close physical contact such as hugging	1	2	3	4	5
Women missing one or both breasts:					
I feel comfortable when others see my mastectomy	1	2	3	4	5
The appearance of my mastectomy could disturb others	1	2	3	4	5
Women who are not missing a breast:					
I feel comfortable when others see my breasts	1	2	3	4	5
The appearance of my breasts could disturb others	1	2	3	4	5

Below are feelings, thoughts, or situations breast cancer patients may experience. Using the scale provided, please indicate how frequently these circumstances have been true in describing your experiences.

1 = Never
2 = Infrequently
3 = Sometimes
4 = Often
5 = Always

	Never	Infrequentl	Sometimes	Often	Always
I feel that people are looking at my chest	1	2	3	4	5
I avoid physical intimacy	1	2	3	4	5
I feel that people are looking at me	1	2	3	4	5
I hide my body when changing clothes	1	2	3	4	5
I need to be reassured about the appearance of my bust	1	2	3	4	5
I feel sexually attractive when I am nude	1	2	3	4	5
I would keep my chest covered during sexual intimacy	1	2	3	4	5
I think my breasts appear uneven to others	1	2	3	4	5
I feel people can tell my breasts are not normal	1	2	3	4	5
Women missing one or both breasts:					
I worry about my prosthesis or padding slipping	1	2	3	4	5

The Body Exposure during Sexual Activities Questionnaire

Instructions:

Below is a list of statements regarding thoughts and behaviors that an individual may experience or engage in during sexual activities. Read each statement carefully and identify how characteristic it is of you and your experiences during sexual activity. Indicate your honest answers by entering a value from 0 to 4 to the left of each statement, using the following scale:

	Never	Rarely	Sometimes	Often	Always or almost always
During sexual activity I am thinking that my partner will notice something about my body that is a turn-off.	0	1	2	3	4
During sex I worry that my partner will find aspects of my physique unappealing.	0	1	2	3	4
During sexual activity I am unaware of how my body looks.	0	1	2	3	4
During sexual activity something about the way my body looks makes me feel inhibited.	0	1	2	3	4
I am comfortable while being undressed by my partner.	0	1	2	3	4
I prefer to keep my body hidden under a sheet or blanket during sex.	0	1	2	3	4
I am comfortable with my partner looking at my genitals during sexual activity.	0	1	2	3	4
When we're having sex, I worry that my partner will find my body repulsive.	0	1	2	3	4
During sexual activity I worry that my partner will think the size or appearance of my sex organs is inadequate or unattractive.	0	1	2	3	4
When it comes to my partner seeing me naked, I have nothing to hide.	0	1	2	3	4
During sexual activity I have thoughts that my body looks sexy.	0	1	2	3	4
I don't like my partner to see me completely naked during sexual activity.	0	1	2	3	4
I expect my partner to be excited by seeing me without my clothes.	0	1	2	3	4
I prefer to keep certain articles of clothing on during sex.	0	1	2	3	4
I am self-conscious about my body during sexual activity.	0	1	2	3	4

During sex I worry that my partner will find the appearance or odor of my genitals repulsive.	0	1	2	3	4
During sexual activity I try to hide certain areas of my body.	0	1	2	3	4
During sexual activity I keep thinking that parts of my body are too unattractive to be sexy.	0	1	2	3	4
There are parts of my body I don't want my partner to see when we are having sex.	0	1	2	3	4
During sexual activity I worry about what my partner thinks about how my body looks.	0	1	2	3	4
During sexual activity I worry that my partner could be turned-off by how parts of my body feel to his/her touch.	0	1	2	3	4
During sexual activity it's hard for me not to think about my weight.	0	1	2	3	4
I feel self-conscious if the room is too well lit when I am having sex.	0	1	2	3	4
I am generally comfortable having parts of my body exposed to my partner during sexual activity.	0	1	2	3	4
During sex I enjoy having my partner look at my body.	0	1	2	3	4
During sex there are certain poses or positions I avoid, because of the way my body would look to my partner.	0	1	2	3	4
During sexual activity I am distracted by thoughts of how certain parts of my body look.	0	1	2	3	4
Prior to or following sex, I am comfortable walking naked in my partner's view.	0	1	2	3	4

BICI

Please respond to each item by circling how often you experience the described feelings or how often you perform the described behaviors.

	Never	Rarely	Sometimes	Often	Always
I am dissatisfied with some aspect of my appearance	1	2	3	4	5
I spend a significant amount of time checking my appearance in the mirror	1	2	3	4	5
I feel others are speaking negatively of my appearance	1	2	3	4	5
I am reluctant to engage in social activities when my appearance does not meet my satisfaction	1	2	3	4	5
I feel there are certain aspects of my appearance that are extremely unattractive	1	2	3	4	5
I buy cosmetic products to try to improve my appearance	1	2	3	4	5
I seek reassurance from others about my appearance	1	2	3	4	5
I feel there are certain aspects of my appearance I would like to change	1	2	3	4	5
I am ashamed of some part of my body	1	2	3	4	5
I compare my appearance to that of fashion models or others	1	2	3	4	5
I try to camouflage certain flaws in my appearance	1	2	3	4	5
I examine flaws in my appearance	1	2	3	4	5
I have bought clothing to hide a certain aspect of my appearance	1	2	3	4	5
I feel others are more physically attractive than me	1	2	3	4	5
I have considered consulting/consulted some sort of medical expert regarding flaws in my appearance	1	2	3	4	5
I have been embarrassed to leave the house because of my appearance	1	2	3	4	5
I fear that others will discover my flaws in appearance	1	2	3	4	5
I have missed social activities because of my appearance	1	2	3	4	5
I have avoided looking at my appearance in the mirror	1	2	3	4	5

Female Sexual Function Index (FSFI)

INSTRUCTIONS: These questions ask about your sexual feelings and responses during the past 4 weeks. Please answer the following questions as honestly and clearly as possible. Your responses will be kept completely confidential.

In answering these questions the following definitions apply:

Sexual activity can include caressing, foreplay, masturbation and vaginal intercourse.
Sexual intercourse is defined as penile penetration (entry) of the vagina.
Sexual stimulation includes situations like foreplay with a partner, self-stimulation(masturbation), or sexual fantasy.

Sexual desire or interest is a feeling that includes wanting to have a sexual experience, feeling receptive to a partner's sexual initiation, and thinking or fantasizing about having sex.

1. Over the past 4 weeks, how **often** did you feel sexual desire or interest?
   - □ Almost always or always
   - □ Most times (more than half the time)
   - □ Sometimes (about half the time)
   - □ A few times (less than half the time)
   - □ Almost never or never

2. Over the past 4 weeks, how would you rate your **level** (degree) of sexual desire or interest?
   - □ Very high
   - □ High
   - □ Moderate
   - □ Low
   - □ Very low or none at all

Sexual arousal is a feeling that includes both physical and mental aspects of sexual excitement. It may include feelings of warmth or tingling in the genitals, lubrication (wetness), or muscle contractions.

3. Over the past 4 weeks, how **often** did you feel sexually aroused ("turned on") during sexual activity or intercourse?
   - □ No sexual activity
   - □ Almost always or always
   - □ Most times (more than half the time)
   - □ Sometimes (about half the time)
   - □ A few times (less than half the time)
   - □ Almost never or never

4. Over the past 4 weeks, how would you rate your **level** of sexual arousal ("turned-on") during sexual activity or intercourse?

- No sexual activity
- Very high
- High
- Moderate
- Low
- Very low or none at all

5. Over the past 4 weeks, how **confident** were you about becoming sexually aroused during sexual activity or intercourse?

- No sexual activity
- Very high confidence
- High confidence
- Moderate confidence
- Low confidence
- Very low or no confidence

6. Over the past 4 weeks, how **often** have you been satisfied with your arousal (excitement) during sexual activity or intercourse?

- No sexual activity
- Almost always or always
- Most times (more than half the time)
- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

7. Over the past 4 weeks, how **often** did you become lubricated ("wet") during sexual activity or intercourse?

- No sexual activity
- Almost always or always
- Most times (more than half the time)
- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

8. Over the past 4 weeks, how **difficult** was it to become lubricated ("wet") during sexual activity or intercourse?

- No sexual activity
- Extremely difficult or impossible
- Very difficult
- Difficult
- Slightly difficult
- Not difficult

9. Over the past 4 weeks, how often did you **maintain** your lubrication ("wetness") until completion of sexual activity or intercourse?

- No sexual activity
- Almost always or always
- Most times (more than half the time)
- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

10. Over the past 4 weeks, how **difficult** was it to maintain your lubrication ("wetness") until completion of sexual activity or intercourse?

- No sexual activity
- Extremely difficult or impossible
- Very difficult
- Difficult
- Slightly difficult
- Not difficult

11. Over the past 4 weeks, when you had sexual stimulation or intercourse, how **often** did you reach orgasm (climax)?

- No sexual activity
- Almost always or always
- Most times (more than half the time)
- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

12. Over the past 4 weeks, when you had sexual stimulation or intercourse, how **difficult** was it for you to reach orgasm (climax)?

- No sexual activity
- Extremely difficult or impossible
- Very difficult
- Difficult
- Slightly difficult
- Not difficult

13. Over the past 4 weeks, how **satisfied** were you with your ability to reach orgasm (climax) during sexual activity or intercourse?

- No sexual activity
- Very satisfied
- Moderately satisfied
- About equally satisfied and dissatisfied
- Moderately dissatisfied
- Very dissatisfied

14. Over the past 4 weeks, how **satisfied** have you been with the amount of emotional closeness during sexual activity between you and your partner?

- No sexual activity
- Very satisfied
- Moderately satisfied
- About equally satisfied and dissatisfied
- Moderately dissatisfied
- Very dissatisfied

15. Over the past 4 weeks, how **satisfied** have you been with your sexual relationship with your partner?

- Very satisfied
- Moderately satisfied
- About equally satisfied and dissatisfied
- Moderately dissatisfied
- Very dissatisfied

16. Over the past 4 weeks, how **satisfied** have you been with your overall sexual life?

- Very satisfied
- Moderately satisfied
- About equally satisfied and dissatisfied
- Moderately dissatisfied
- Very dissatisfied

17. Over the past 4 weeks, how **often** did you experience discomfort or pain during vaginal penetration?

- Did not attempt intercourse
- Almost always or always
- Most times (more than half the time)
- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

18. Over the past 4 weeks, how **often** did you experience discomfort or pain following vaginal penetration?

- Did not attempt intercourse
- Almost always or always
- Most times (more than half the time)
- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

19. Over the past 4 weeks, how would you rate your **level** (degree) of discomfort or pain during or following vaginal penetration?

- Did not attempt intercourse

- Very high
- High
- Moderate
- Low
- Very low or none at all

Perspectives on Body Image, Sexual Functioning and Breast Cancer Survivorship

What are your thoughts or feelings about your body image and how it has changed since being diagnosed with cancer? This can include both positive changes, such as feeling more confident and happy with your body, as well as negative changes.

_____
_____
_____
_____
_____

What are your thoughts or feelings about your sexuality since being diagnosed with cancer? This can include both positive changes in your sexuality, such as having an improved sex life or closeness with your partner, as well as negative ones.

_____
_____
_____
_____
_____

Thank you for completing the survey. If you would like to be included in a drawing for 1 of 15 $25 Walmart gift cards please provide your contact information in the space provided. Following the completion of the study, the fifteen winners of the draw will be notified via email, and a $25 gift card will be mailed to them at their stated residence. Please note that participation in the drawing is optional and your contact information will not be linked to your survey responses.

Contact Information

Name: _____
Address:_____
Email Address:_____

If you would like to provide the email address of a friend or family member who might also be interested in participating in a confidential online survey for women who have been diagnosed and treated for breast cancer please enter their email address in the space provided below. Please note that this step is optional and will not be linked to your survey responses.

Email Address of Potentially Interested Participant(s):_____

Below are some resources you can contact if you wish to discuss any of the topics covered in the survey or if you would like more information about these topics. Please print this page for your records.

YourShoes 24/7 Breast Cancer Support Center
Y-ME National Breast Cancer Organization
1-800-221-2141
http://www.y-me.org/
A 24-hour free and confidential hotline where women can speak with a trained peer counselor who is also a breast cancer survivor. YourShoes peer counselors are available 365 days/year and can be contacted via phone or website, with real-time interpreters available in more than 150 languages.

SHARE - Self-Help for Women with Breast or Ovarian Cancer
1501 Broadway, Suite 704A
New York, NY 10036
Breast Cancer (toll-free in English & Spanish) 1-866-891-2392
info@sharecancersupport.org
A 24-hour free and confidential hotline where women can speak with a trained peer counselor who has had breast or ovarian cancer. Counselors are available 365 days/year who speak English, Spanish, and 10 other languages and can be contacted via phone or website.
Cancer Care, Inc.

Living Beyond Breast Cancer
http://www.lbbc.org
1-888-753-5222
354 West Lancaster Ave., Suite 224
Haverford, PA 19041
Offers educational programs and services to women and families affected by breast cancer. Programs include a toll-free Survivors' Helpline (1-888-753-5222), a free quarterly newsletter, publications for African-American and Latina women, and networking programs for young survivors and women of color.

Young Survival Coalition
http://www.youngsurvival.org
1-877-YSC-1011 (1-877-972-1011)
61 Broadway, Suite 2235
New York, NY 10006
This website provides educational and support services for young women who have been diagnosed with breast cancer, online bulletin boards on which young survivors can communicate with one another, informational brochures and a monthly newsletter. The organization has affiliate branches that host meetings in more than a dozen locations across the United States.

Cancer Care
1-800-813-4673
Free counseling for cancer patients and their families. Financial assistance, information and referrals, community and professional education. Teleconference programs. On-going telephone and in-person support groups.

Study PI Contact Information:

Lindsey Rosman, B.A.
Doctoral student, Department of Psychology, East Carolina University
RosmanL09@students.ecu.edu

Heather Littleton, Ph.D.
Faculty Sponsor and Assistant Professor, Department of Psychology, East Carolina University
LittletonH@ecu.edu

Appendix C

AD for online posting

Hello, my name is Lindsey Rosman and I am a doctoral student at East Carolina University in psychology. I am currently conducting research on body image concerns and long-term sexual adjustment in women diagnosed and treated for early-stage breast cancer. Through this research, I hope to learn about women's sexual experiences in the context of cancer survivorship and identify factors that potentially affect women's post-treatment sexual functioning.

If you are a woman 18 years of age or older, currently in a relationship, who has been diagnosed with early-stage breast cancer and has completed treatment, and who currently resides in the United States, you are eligible to participate in our confidential survey that is available on-line. Completing this survey should take half an hour or less. Fifteen women who complete the survey will be selected to receive a $25 Walmart gift card.

If you would like to know more information about this study or would like to participate in the survey, please click on the link provided here (*link to online survey information page*).

Thank you for your interest and help!

If you have any questions, please contact me at stresscopelab@ecu.eduor the faculty supervisor for this research, Dr. Heather Littleton, at LittletonH@ecu.edu.

Appendix D
Study Flyer

Body Image and Sexual Functioning in Breast Cancer Survivors

Participate in a brief, confidential online survey on body image concerns and sexual adjustment in women treated for early-stage breast cancer. Help contribute to knowledge about women's sexual experiences in the context of cancer survivorship and what affects women's post-treatment sexual adjustment.

Open to U. S. women 18 years of age or older, currently in a relationship, who have completed treatment for Stage I, II, or IIIa breast cancer (diagnosis had never exceeded Stage IIIa).

Completing this survey should take less than 30 minutes. To thank you for your participation, you can enter to win a drawing for 1 of 15 $25 Walmart gift cards.

For more information or to participate in this research study, please visit: http://www.ecu.edu/survey/BCbodyimage

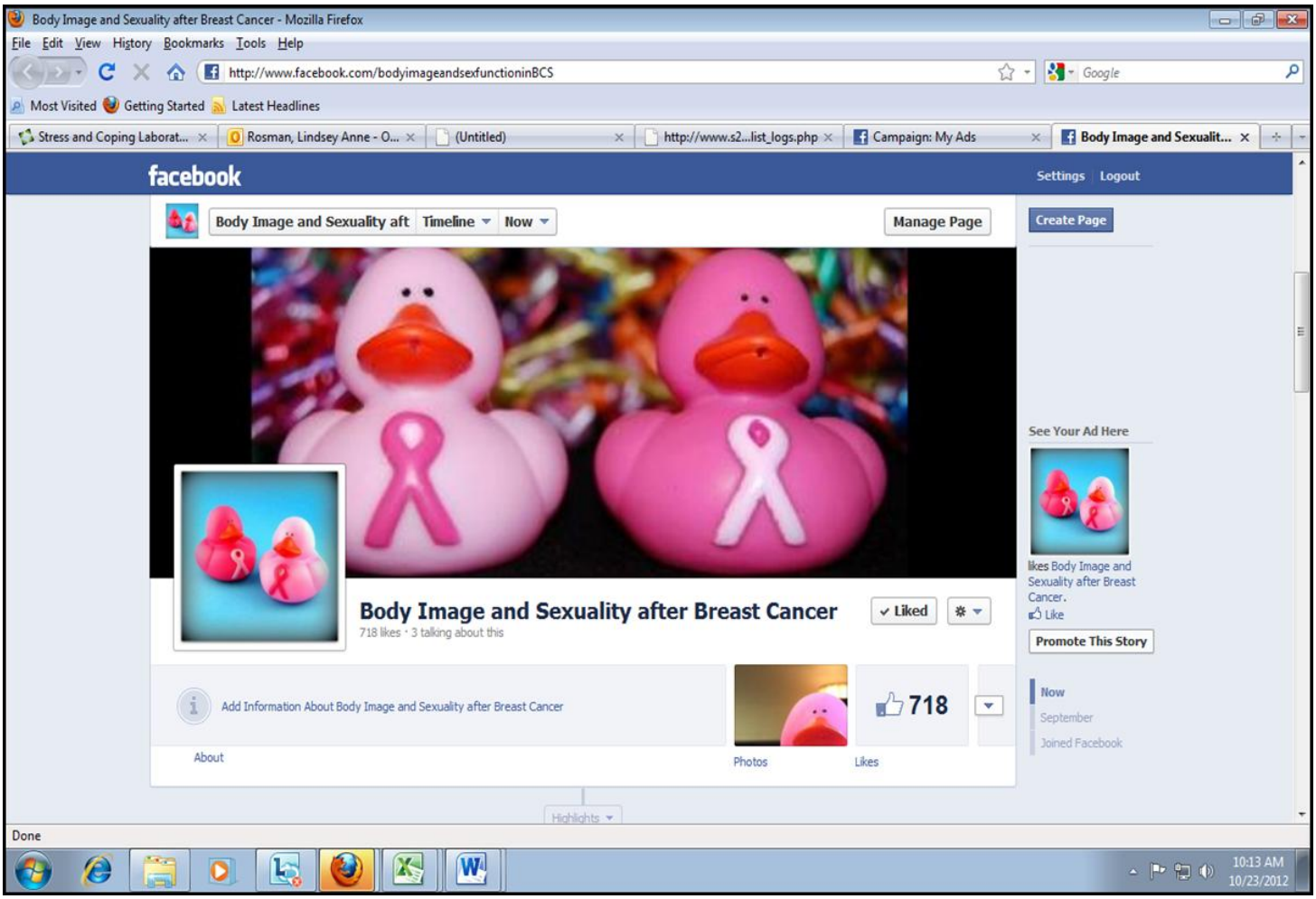
You can also contact us at stresscopelab@ecu.edu or LittletonH@ecu.edu.

Lindsey Rosman, B.A.
Doctoral student
Department of Psychology
East Carolina University

Heather Littleton, Ph.D.
Assistant Professor
Department of Psychology
East Carolina University

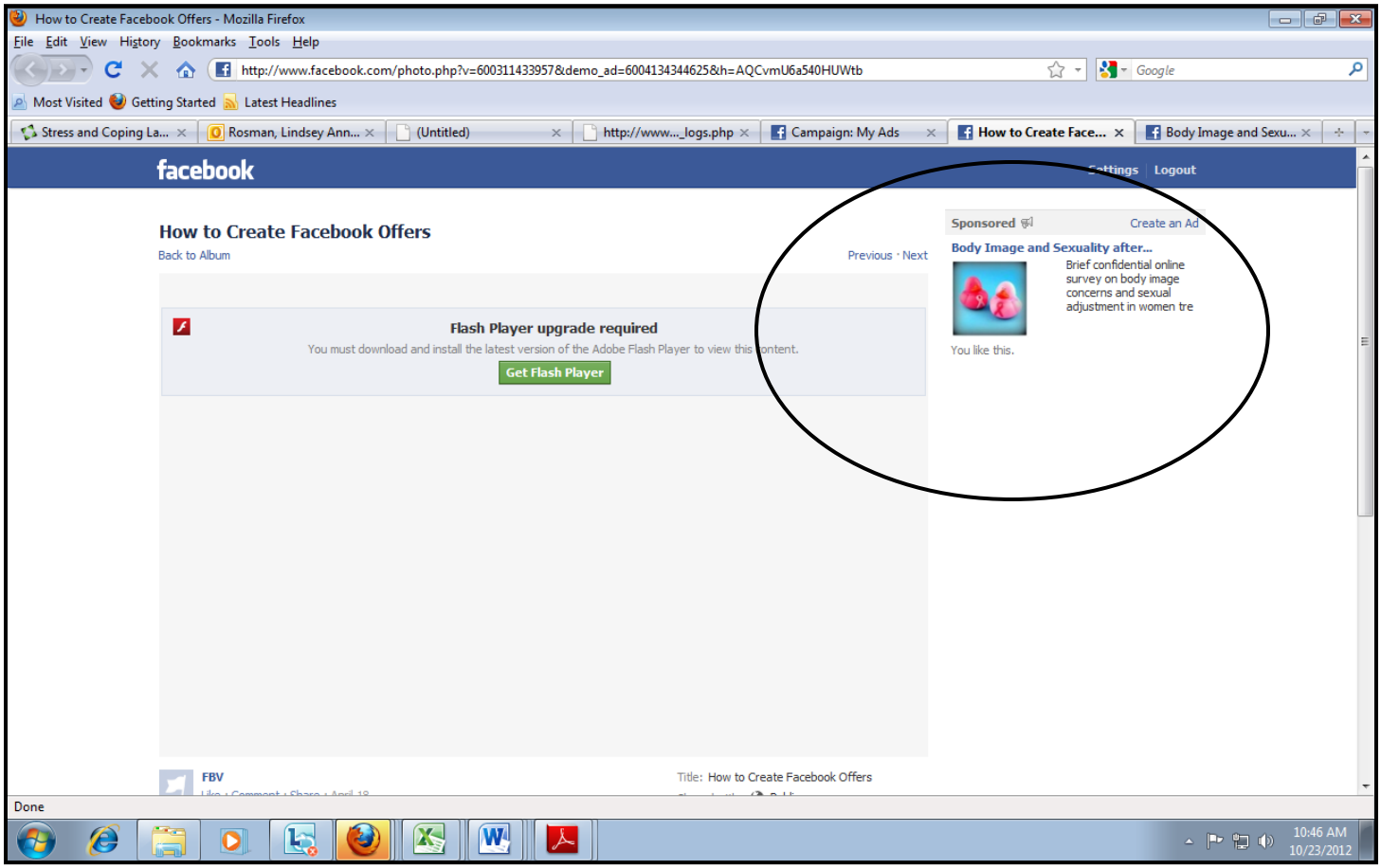
Appendix E

Screenshot of study Facebook page



Appendix F

Screenshot of Facebook advertisement



Appendix G

East Carolina University

Consent to Participate in Research that is Greater than Minimal Risk

Information to Consider Before Taking Part in This Research

Title of Research Study: Body Image and Sexual Functioning in Breast Cancer Survivors

Principal Investigator: Lindsey Rosman, B. A., Doctoral student, Department of Psychology, East Carolina University

Faculty Sponsor: Heather Littleton, Ph.D., Assistant Professor, Department of Psychology, East Carolina University

Institution/Department or Division: Department of Psychology, East Carolina University

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Researchers at East Carolina University (ECU) study diseases, health problems, environmental problems, behavior problems and the human condition. Our goal is to try to find better ways to improve the lives of you and others. To do this, we need the help of people who are willing to take part in research.
The person who is in charge of this research is called the Principal Investigator. The Principal Investigator may have other research staff members who will perform some of the procedures.

You do not have to take part in this research. Take your time and think about the information that is provided. If you want, have a friend or family member go over this form with you before you decide. It is up to you. If you choose to be in the study, you should agree when you are comfortable that you understand the information provided below. If you do not want to take part in the study, you should not agree. That decision is yours and it is okay to decide not to volunteer.

This form explains why this research is being done, what will happen during the research, and what you will need to do if you decide to volunteer to take part in this research.

Why is this research being done?
The purpose of the current study is to examine body image concerns and long-term sexual adjustment in women diagnosed and treated for early-stage breast cancer. We are asking you to take part in this research. However, the decision is yours to make. By conducting this research, we hope to learn about women's sexual experiences in the context of cancer survivorship and identify factors that potentially affect women's post-treatment sexual functioning.

Why am I being invited to take part in this research?
You are being invited to take part in this research because you are a woman age 18 years and older, currently in a relationship, who has been diagnosed with early-stage breast cancer and has completed treatment. If you volunteer to take part in this study, you will be one of about 300 women to do so.

What other choices do I have if I do not take part in this research?
You have the choice of not taking part in this research study. You can also close your browser at any time if you do not wish to complete the study.

Where is the research going to take place and how long will it last?
The current study is a confidential online survey and will take approximately 30 minutes to complete.

What will I be asked to do?
You will be asked to complete a number of online questionnaires. These questionnaires will include questions about your current sexual functioning, sexual experiences you have had, body image concerns, and emotional distress. You will also be asked questions about your cancer treatment history, including your disease stage at diagnosis, and type of surgery.

Once you complete the study, you will be provided with an area where you can enter your contact information if you would like to be included in a drawing for 1 of 15 $25 Walmart gift cards. Following the completion of the study, the fifteen winners of the draw will be notified, and a $25 gift card will be mailed to them at their stated residence. In addition, you will be asked if you would like to provide the email address of a friend or family member who might also be interested in participating in a confidential online survey for women who have been diagnosed and treated for breast cancer.

What possible harms or discomforts might I experience if I take part in the research?
The primary risk to you is emotional upset and discomfort as a result of completing study questionnaires. The online questionnaires will ask about your current sexual functioning as well as questions about body image, emotional distress, and your cancer treatment history.

List of Resources
You should be aware of national resources that can assist you with the issues discussed in this study. This information will also be provided at the end of the survey.

YourShoes 24/7 Breast Cancer Support Center
Y-ME National Breast Cancer Organization
1-800-221-2141
http://www.y-me.org/
A 24-hour free and confidential hotline where women can speak with a trained peer counselor who is also a breast cancer survivor. YourShoes peer counselors are available 365 days/year andcan be contacted via phone or website, with real-time interpreters available in more than 150 languages.

SHARE - Self-Help for Women with Breast or Ovarian Cancer
1501 Broadway, Suite 704A
New York, NY 10036

Breast Cancer (toll-free in English & Spanish) 1-866-891-2392
info@sharecancersupport.org
A 24-hour free and confidential hotline where women can speak with a trained peer counselor who has had breast or ovarian cancer. Counselors are available 365 days/year who speak English, Spanish, and 10 other languages and can be contacted via phone or website.

Living Beyond Breast Cancer
http://www.lbbc.org
1-888-753-5222
354 West Lancaster Ave., Suite 224
Haverford, PA 19041
Offers educational programs and services to women and families affected by breast cancer. Programs include a toll-free Survivors' Helpline (1-888-753-5222), a free quarterly newsletter, publications for African-American and Latina women, and networking programs for young survivors and women of color.

Young Survival Coalition
http://www.youngsurvival.org
1-877-YSC-1011 (1-877-972-1011)
61 Broadway, Suite 2235
New York, NY 10006
Website provides educational and support services for young women who have been diagnosed with breast cancer, online bulletin boards on which young survivors can communicate with one another, informational brochures and a monthly newsletter. The organization has affiliate branches that host meetings in more than a dozen locations across the United States.

Cancer Care
1-800-813-4673
Free counseling for cancer patients and their families. Financial assistance, information and referrals, community and professional education. Teleconference programs. On-going telephone and in-person support groups.

What are the possible benefits I may experience from taking part in this research?
It is likely that you will not directly benefit from your participation. Information obtained from the research will potentially lead to a better understanding of women's sexual functioning and experiences after diagnosis and treatment for breast cancer.

Will I be paid for taking part in this research?
There is no compensation for the time you volunteer while being in this study. However, women who chose to participate will be eligible for inclusion in drawing for 1 of 15 $25 Walmart gift cards at the conclusion of the study.

What will it cost me to take part in this research?
There is no cost associated with participation in this study.

How will you keep the information you collect about me secure and how long will you keep it?

All online information will be stored on a secure server. All identifying information, including email addresses, will be removed from your data before downloading it.

What if I decide I do not want to continue in this research?
Participating in this study is voluntary. If you decide not to be in this study after it has already started, you may stop at any time by closing your browser window.

What if I get sick or hurt while I am in this research?
The policy of East Carolina University does not provide for payment or medical care for research participants because of physical or other injury that result from this research study.

Who should I contact if I have questions?
The people conducting this study will be available to answer any questions concerning this research, now or in the future. You may contact the Faculty Sponsor, Dr. Heather Littleton at(252) 328-6488.

If you have questions about your rights as someone taking part in research, you may call the ECU Office for Human Research Integrity (OHRI) at phone number 252-744-2914 (days). If you would like to report a complaint or concern about this research study, you may call the Director of OHRI, at 252-744-1971.

I have decided I want to take part in this research. What should I do now?
By clicking the submit button you are stating that you have read the above information and are giving your consent to participate in this study. You may withdraw at any time by closing your browser window.

Please print a copy of this form for your records.