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An Exploration of Appearance-Related Issues of Breast Cancer Treatment on Sense of Self, Self-Esteem, and Social Functioning in Women with Breast Cancer

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An Exploration of Appearance-Related Issues of Breast Cancer Treatment on Sense of Self, Self-Esteem, and Social Functioning in Women with Breast Cancer

Abstract

ABSTRACT AN EXPLORATION OF APPEARANCE-RELATED ISSUES OF BREAST CANCER TREATMENT ON SENSE OF SELF, SELF-ESTEEM, AND SOCIAL FUNCTIONING IN WOMEN WITH BREAST CANCER Margaret M. Preston Joretha N. Bourjolly We, as individuals, and in most cases, become the designers of our external appearance. Through hair styles, cosmetics, grooming behaviors, tattoos, piercing, and our style of dress, our outward appearance sends messages about ourselves to others. This outward appearance is the primary focus in identity recognition and first impressions. As humans, we are influenced by our social interactions and the impressions we give and receive from others. To date, very little attention has been given related to altered appearance in women who are receiving treatment for breast cancer. The personal impact of appearance-related changes due to cancer treatment can be devastating for most women. The importance of looking like yourself (the “you” that you created) throughout the cancer process has received little attention by the social work profession. The purpose of this qualitative descriptive study is to describe the appearance-related issues involving breast cancer treatment and whether they affect one’s sense of self, social functioning, and self-esteem from the women themselves. Twelve women (N=12) who had been treated for breast cancer participated in audio taped interviews. The analysis of the interviews revealed that appearance-related issues resulting from breast cancer treatment were a major source of disruption of the women’s sense of self which affected their self-esteem and areas of social functioning. The findings were consistent with interpersonal, cognitive behavioral, and status generalization theories which describe that people are social in nature, require acceptance by others, and can be discriminated against based on their appearance. Often times altered appearance can lead to misperceptions or assumptions about oneself and how one feels they are being perceived by others. The rich description provided in this study identifies the need to further investigate appearance-related issues resulting from breast cancer treatment to gain an understanding of how social workers can better serve this population.

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AN EXPLORATION OF APPEARANCE-RELATED ISSUES OF BREAST CANCER
TREATMENT ON SENSE OF SELF, SELF-ESTEEM, AND SOCIAL FUNCTIONING
IN WOMEN WITH BREAST CANCER

Margaret M. Preston

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IN WOMEN WITH BREAST CANCER

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Margaret M. Preston

DEDICATION

To the light that leads me. I call him father.

Thy will be done.

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I would like to begin by thanking my family: My husband, Phil, you're my hero. My daughter: Carla, thanks for believing in me. I thank you both for your love and support. My dogs: Millie and Spock, who waited patiently many nights for me to go to bed.

I thank all of the pivotal people in my life beginning with my parents who are watching from above, Michael Preston, my brother, Sam Joseph, Dr. Barbara Lewis, Dr. Pat Lewis, Dr. Gerry Dawson, Martha Madigan, Bill Robbins and Dr. Hack Chung.

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Most importantly, I wish to extend my sincere appreciation to all of the brave women who agreed to tell their stories. Without them there would be no study. May this study help to further the goal of addressing concerns related to breast cancer treatment.

ABSTRACT

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CHAPTER 1

Introduction

It has been well documented by both interpersonal and cognitive theorists that a person's thoughts, beliefs, and assumptions shape their perceptions and interpretations related to self, others, and situations (Beck, 1979; Ellis & Harper, 1961; Freeman & Dattilio, 1992; Maltz, 1960; Sullivan, 1953). Often, one's assumptions or faulty beliefs can lead to negative and irrational thoughts resulting in feelings of anxiety, depression, and avoidant behaviors. Status generalization theory reinforces these irrational beliefs by creating performance expectations. One of the central themes of status generalization theory relates to physical attractiveness and the belief that "beautiful is good". Status generalization theory suggests that attractive individuals are more competent than less attractive individuals. In this study the aim was to explore whether appearance-related issues of breast cancer treatment resulted in assumptions about oneself that interfered with their overall sense of self, self-esteem, and social functioning. The aim was also to determine the impact appearance-related side effects of breast cancer treatment had on sense of self, self-esteem, and social functioning.

The past two decades have given us much information and new technologies related to the diagnosis and treatment of breast cancer. To date, understanding the appearance-related concerns women have as they move through their breast cancer journey has not been widely explored. Becoming aware of this aspect of treatment can make it possible for clinical social workers to target these specific concerns and provide the necessary education, resources, and interventions to women receiving treatment for breast cancer. Does altering one's appearance matter to women who are in treatment for

breast cancer? The study will allow breast cancer survivors to tell their story, enabling the reader to get a first hand description of any appearance related concerns that surfaced while the women navigated through their breast cancer journey and how these concerns affected their functioning.

1.1. Breast Cancer Statistics

“Somewhere in the world, a woman dies of breast cancer every 68 seconds” (Susan G. Komen for the Cure, 2009). According to the American Cancer Society breast cancer is the second leading cause of cancer death in women (American Cancer Society, 2009). It was estimated that in 2009, a staggering 192,370 new cases of invasive breast cancer were diagnosed and 40,170 women would die from breast cancer. Recent reports identify breast cancer as one of the most frequently diagnosed cancers among women (The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, 2009; National Breast Cancer Foundation, 2009). Currently a woman living in the United States has a 1 in 8 lifetime risk of developing breast cancer (American Cancer Society, 2009). This risk was about 1 in 11 in 1975 (National Breast Cancer Coalition, 2009). There is about a 1 in 35 chance that breast cancer will be responsible for a woman’s death (American Cancer Society, 2009).

It is no wonder that women tend to shudder when awaiting the results of their yearly mammogram. This dreaded disease can wreak havoc on the most confident women dismantling their very sense of self. A breast cancer diagnosis ravages the mind, body and spirit of a woman and brings serious doubts to her ability to remain the same woman she was before the diagnosis.

Following a diagnosis of breast cancer a number of areas in a woman's life become impaired (Beatty, Oxlad, Koczwara, & Wade, 2008). According to Frierson and Anderson (2006), a woman's responses related to her body changes as a result of having breast cancer consist of "psychological adjustment, social adjustment, relationships with sexual partners, physical symptoms, and related concerns" (p.173)

1.2. Ethnicity and Breast Cancer

This devastating disease strikes women of all ethnic groups. According to the Centers for Disease Control and Prevention (2010) breast cancer affects all women regardless of ethnicity. White women are diagnosed more often than Latina/Hispanic, African American, Asian or Native American women; although, on average, African Americans are more likely to die from the disease. Breast cancer is the number one cause of death in Hispanic women. Breast cancer is the second leading cause of cancer death in women who include White, Black, Asian/Pacific Islanders and American Indian/Alaskan Native women. White, Hawaiian and African American are reported to have the highest incidence of invasive breast cancer in the United States. Korean, American Indian and Vietnamese women have the lowest incidence of invasive breast cancer in the United States.

As reported by the American Cancer Society (2009), "African American women with breast cancer are less likely than white women to survive five years" (p. 8). They are identified as having the highest death rate from breast cancer and are more likely to be diagnosed with a later stage than white women. African American women's five-year survival rate is 74% compared to 88% in White women (Sisters Network, 2009). These observed differences in survival rates have been attributed to two factors which include a

later stage at detection and poorer stage specific survival. Contributing to these factors are the lack of health insurance, unequal access to medical care, lower socioeconomic status, the presence of other illnesses as well as disparities in treatment.

A report by Susan G. Komen for the Cure (2009) recognizes breast cancer as the most common cancer among Latina/Hispanic women. This is attributed to the fact that they are less likely to have mammography screenings. This population is more likely to be diagnosed at a later stage of breast cancer. Some factors contributing to these statistics may include low income, lack of medical insurance, lack of getting prompt follow-up after an abnormal mammogram, lack of education, lack of cancer awareness as well as cultural and language barriers.

1.3. Age/Gender

Men. Although rare in men, it was estimated that 1,910 new cases of invasive breast cancer was diagnosed in men in 2009 (American Cancer Society, 2009). The lifetime risk for men in getting breast cancer is about 1 in 1,000. The survival rates for men are about equal to those in women when looking at the same stage of breast cancer (American Cancer Society, 2009). Cancer Survival Rates (2009) reported that breast cancer survival rates have been lower for men due to late detection and lack of awareness. A recent newsletter from the Susan G. Komen for the Cure (2009) reported that 440 men die of breast cancer each year in the United States. The strongest risk factor for breast cancer in men is Klinefelter's syndrome. This syndrome is related to high levels of estrogen in men who are born with two X chromosomes instead of XY (Susan G. Komen for the Cure, 2009).

Lesbians. There is a reported greater risk of breast cancer in lesbians and women who partner with women (Susan G. Komen for the Cure, 2009). This has absolutely nothing to do with sexual orientation but is linked to other risk factors which may include not having children and having lower rates of screening mammograms. According to reports, reproductive health issues are identified as a woman's main link to the healthcare system where issues such as breast exams and yearly mammograms are discussed. It is believed that because fewer lesbians have children they may not seek routine health care, lessening the opportunities to have the screening tests for breast cancer (Susan G. Komen for the Cure, 2009).

According to the Centers for Disease Control and Prevention (2009) the risk of developing breast cancer as well as the risk of dying from breast cancer increases with age. According to a report by Imaginis (2010), about 77% of cases of breast cancer occur in women over 50 years of age. The statistics for age are as follows: The probability of developing breast cancer within ten years for women age 20 is 1 in 1,985. This rate increases with age, by age 30 it jumps to 1 in 229. Women age 40 have a 1 in 68 chance of developing breast cancer within a ten year period. Chances continue to increase and at age 50 a startling 1 in 37, age 60 reporting 1 in 26 and age 70, one in 24. Every woman is at risk for breast cancer. The National Breast Cancer Coalition (2009) reports that 90-95% of all women who develop breast cancer do not have a family history of the disease; therefore, attributing only 5-10% of breast cancers to heredity.

1.4. Survival

Breast cancer statistics indicate that breast cancer is less common in younger women, i.e., women in their thirties. However, younger women appear to have more

aggressive cancer with a lower survival rate than older women. According to a report by Imaginis (2008) each patient's individual tumor characteristics, state of health, genetic background, etc. will impact her survival rate. Levels of stress, immune function, will to live, and other immeasurable factors play a role in the survival rate. According to Cancer Survival Rates (2009) the current 5 year breast cancer survival rate is 86% and the ten year survival rate is 76%. The survival rate for women whose breast cancer has not metastasized is 96%. It is important to consider the stage at which the cancer is detected. Early stage breast cancers are associated with high survival rates.

1.5. Breast Cancer Treatments

Staging. Lange (1998) described a process of staging used to assess the size and location of the cancer. This process also determines who should get what treatment. Staging is based on the size of the tumor, the presence of cancer cells in the lymph nodes, and metastasis to other organs. Stage 0 indicates a very early form of cancer, Stage 1 indicates that the tumor is approximately $\frac{3}{4}$ inch or smaller. Stage II is usually about $\frac{3}{4}$ to 2 inches. The axillary lymph nodes may or may not be positive for cancer. At stage III the tumor is larger than 2 inches and axillary lymph nodes are positive. Stage IV indicates advanced, metastatic breast cancer. In addition to the breast cancer characteristics, there are other factors that play a significant role in a patient's survival. It is important to look at genetic predisposition as well as other non-related health issues.

BRCA Mutation. BRCA1 and BRCA2 are two genes that have been associated with the development of breast cancer. According to Lange (1998) these specific genes found on Chromosome 17 correlate with an increased incidence of hereditary breast cancer. BRCA mutations do not guarantee that a person will develop breast cancer.

There is BRCA gene testing available but it is not recommended for everyone. Women who have a family history of BRCA mutation should get screened for the mutation. Genetic testing is most often accompanied with a qualified genetic risk counselor to discuss any ramifications.

Mastectomy. When it has been determined that the cancers have metastasized beyond the ducts and lymph nodes of the breast they are considered invasive. These cancers are called regional stage at which point the oncologist would apply a numeric rating based on the system described above. The surgical option becomes removal of the entire breast, also known as a mastectomy. This has been a dreaded treatment option for women with breast cancer for many years; however, today the techniques are much less disfiguring. In some cases, as a precautionary measure, where there has been a family history of breast cancer placing them at a high risk for the disease, some women will choose to undergo a “prophylactic” mastectomy (Lloyd, et al., 2000).

Lumpectomy. Over the past two decades the treatment options for breast cancer have changed encouraging women to take ownership of their treatment decisions. The lumpectomy has become the breast cancer treatment of choice due to its conservative approach in saving the breast. This breast-saving treatment option removes just the malignant tumor, marginal surrounding tissue, and lymph nodes which are sent for pathological analysis. This procedure is usually followed by radiation therapy to destroy any cancer cells that may have been present in the breast area (American Cancer Society, 2008).

Radiation Therapy. Radiation Therapy (XRT) uses what we have commonly known as x-rays to deliver higher doses and intensity of radiation to destroy the ability of

cells to grow and multiply in women who are being treated for breast cancer (Lange, 1998). Radiation therapy, described by Lange (1998), as a painless procedure with minimal side effects treats only the site of the original cancer by using a sophisticated machine known as a linear accelerator. This machine is positioned over the patient providing beams from different angles to treat the breast area. According to Robinson and Petrek (1994), the radiation therapy doesn't usually begin until about four to six weeks after surgery to give the body time to heal. Recent data from a meta-analysis suggests that radiation may offer therapeutic benefits for patients with Stage II disease with one to three positive lymph nodes (Buchholtz et al., 2008).

Chemotherapy. Cytotoxic drugs, known as chemotherapy, are the most powerful tools used to kill cancer cells (Lange, 1998). These anti-cancer drugs are administered to prevent the cancer cells from growing and dividing. Chemotherapy is a systemic treatment, unlike surgery and/or radiation which focuses on a part of the body, chemotherapy reaches all parts of the body. This is necessary when it is suspected that cancer cells have metastasized to other parts of the body.

There are numerous different chemotherapy drugs which are designed to interfere with the process of cell division. An oncologist selects a combination of the drugs designed for each individual patient based on the characteristics of the breast cancer and the patient's overall health (Lange, 1998).

The chemotherapy drugs are administered orally, in a pill form, or by injection into a vein. This injection usually, but not always, involves the placement of a port. This port is a device that is surgically inserted under the skin, just below the collar bone or arm where it is easily accessible. The port is a way to administer the drugs with the least

damage to the lining of a woman's veins. Ports can also be used for drawing blood during doctor or clinic visits (Lange, 1998).

Reconstruction. For many years the standard treatment for women with breast cancer was the radical mastectomy. The consequences of such surgery consisted of cosmetic deformity, loss of arm function, and significant pain and tightness across the chest (Ganz, 2008). Many women who have had a mastectomy have chosen to have their breast reconstructed to enhance their self-image. This is a personal decision and may not be right for everyone. According to Lange (1998), some women choose to view their scars as battle scars electing to forego reconstruction.

Mounting evidence of the efficacy of breast conserving surgery in early stage breast can now lead to less invasive procedures (Frierson & Andersen, 2006). In the past two decades the trauma of breast cancer surgery has diminished substantially lessening the episodes of cosmetic deformity and restoring body image with reconstructive surgical implants (Ganz, 2008). Immediate reconstruction was not widespread until the turn of the 21st century. Today, due to the successful use of cancer screenings, women have been diagnosed at earlier stages resulting in less radical surgeries (Frierson & Anderson, 2006). However, women are still suffering from both physical and psychological problems as a result of cancer treatments. The life-threatening diagnosis of breast cancer itself begins a woman's physical and psychological journey. According to Pruzinsky (2002), "Research on the psychological effects of breast reconstruction consistently documents post surgical body image improvement" (p. 445).

Contemporary surgeries for breast cancer consist of mastectomy, mastectomy with reconstruction, or lumpectomy. All of these treatment options can induce a level of

scarring and disfigurement to a woman's breast. An experimental study by Ogden and Lindridge (2008) concluded that scarring resulted in lower ratings of attractiveness and self-esteem.

Frierson and Andersen (2006) reported that the majority of women receiving breast reconstruction are between the ages of 35 years and 64 years of age. They suggested several factors contributing to the lower rates of reconstruction for older women, which may include higher rates of medical comorbidities raising the risk for complications and less concern, for some, about having an altered breast. Also, rates of reconstruction were higher among women with higher incomes.

Breast reconstruction can be done by transferring tissue from another part of the body. This procedure is known as a myo-cutaneous flap, most often referred to as a "flap" (Lange, 1998). Today, there are many different types of flaps. One of these is known as the TRAM flap. TRAM flaps are constructed by pulling a muscle from the abdomen along with fat and skin without cutting the original blood vessels. The flap is then shaped into the form of a breast requiring no implant. A cosmetic benefit of this procedure is that it also gives the woman what is known as a "tummy tuck".

Another flap, referred to as a LAT flap, takes a portion of the muscle, fat, and skin covering from the upper back and pulls it through a skin tunnel under the arm to reconstruct the breast. This procedure may require a synthetic implant to match the other breast because in most cases it does not provide enough bulk (Lange, 1998).

A free flap is a procedure that also removes muscle, fat, and skin from other parts of the body, usually the abdomen (SIEA flap or DIEP flap) and buttocks (GAP flap). However, in this case the blood supply is cut requiring a microsurgical procedure to re-

connect the thin blood vessels. These tiny blood vessels are responsible for supplying nutrients to the tissue (perforators). This technique is referred to as perforator flap breast reconstruction (Wellnesspick, 2010).

1.6. Side Effects of Treatment and Altered Appearance

Breast cancer treatment may involve surgery, chemotherapy, radiotherapy and in some cases, all three. Although the trauma of a more radical surgery may be diminished, the alternative treatments can be extremely damaging to a woman's physical and psychological health. Some of the treatment related side effects are scarring, from surgery, weight loss/weight gain, swelling and changes to both reproductive and sexual functioning. Harcourt and Frith (2008), reported concerns from breast cancer patients receiving chemotherapy that these changes in appearance can reveal disease status to others. Moorey (2007) described:

Cancer and its treatment can have devastating effects on the body. In its early stages the disease itself may not present with much change in physical appearance, but the treatment the patient undergoes to reach a cure or remission may be disfiguring. Surgery is the most obvious example of this, such as the amputation of a breast or extensive excision of the skin surrounding a melanoma. But less invasive treatments also cause body changes, such as hair loss and weight loss from chemotherapy or the menopausal effects of endocrine therapy. In the later stages the disease itself may cause significant problems, perhaps with large visible tumors or ulcers or the general effects of extreme weight loss. Whether these changes are immediately visible to the outside world, as in skin and head and neck cancers, or are more hidden, they nonetheless pose a threat to body integrity (p. 72).

Chemotherapy treatment for women with breast cancer can have a devastating effect on the already vulnerable self. Women undergoing chemotherapy experience a number of treatment related physical problems. Some of these problems have been identified as nausea and vomiting, fatigue, change in weight, mouth ulcers, dark circles

around the eyes, ridges in finger and toe nails, alopecia and dry and discolored skin. More serious side effects can be anemia, infection and bleeding (Breast Cancer Survivor Guide, 2009). Chemotherapy has been known to damage a woman's ovaries and cause infertility. Therefore, women associate chemotherapy with premature menopause and the negative results it may have on their appearance and body image (Harcourt & Frith, 2008).

Side effects from radiation therapy vary from patient to patient. Radiotherapy can cause skin to turn red (similar to sunburn) or tan and sometimes swelling and soreness will occur in the treated area (American Cancer Society, 2009). The outline marks for treatment ports using colored ink concerns some patients in addition to the visible dermatological changes (White, 2002). White reported:

These appearance related changes resulting from treatment are often ranked as more severe than side effects such as nausea, insomnia, breathlessness, and fatigue. Patients' responses to such changes, though not always apparent, can significantly affect their self-confidence and overall well-being and therefore warrant careful consideration. In some instances, diminished self-confidence does not return to pretreatment levels, even when prior appearance is restored (p. 381).

1.7. Chemotherapy-Induced Alopecia

Any one of these changes can be difficult to adjust to; however, the research literature that follows emphasizes that when a woman experiences hair loss, particularly on her head, eyebrows and eyelashes, the implications are enormous, both physically and psychologically. "From early childhood, women learn the importance of hair. Mothers style their young daughters locks, who soon associate hair with feminine beauty" (Bauman, 2008, p. 65). According to Chassin (2008), it is perfectly normal to mourn the loss of the hair. She emphasizes that women actually go through the grief stages because

they have lost a part of themselves. Moorey (2007) stated that hair loss for some women may be more distressing than the loss of her breast. Moorey identified depression, shame and loss of confidence related to alopecia in women with breast cancer. As described by Moorey, “It is the most feared side effect of chemotherapy for 56% of women, and as many as 8% may be at risk of refusing chemotherapy because of this fear” (p. 83).

Lemieux, Maunsell and Provencher (2007), in their literature review of 38 articles, concurred that chemotherapy-induced alopecia was considered as a traumatic side effect of treatment which could lead to refusal of chemotherapy and could possibly have an impact on body image.

According to The Breast Care Site (2010), hair loss is reported to be a substantial issue for women of color. African-American women reported that they obsess about their hair and their fear of hair loss. Whether wearing their hair natural, in Afro’s, cornrows, weaves, or having it straightened, hair and the loss of it, has long been a focus for African American women. In Africa much importance was placed on grooming and styling hair as a cultural ritual. ‘African-American hair is viewed as a political statement, a matter of pride, and a way in which to show individuality’ (The Breast Care Site, 2010). African-American women, like most women, associate ‘femaleness’ with their hair (Johnson & Harris, 2001).

Frith, Harcourt and Fussell (2007) argued that anticipating and preparing for altered aspects of appearance, specifically alopecia, can be a form of coping for these women. Preparing helps these women to feel more in control of the treatment related side-effects. Four key themes were identified from their interview studies which were

identified as: (1) anticipating hair loss, (2) coming to terms with the inevitability of hair loss, (3) becoming ready, and (4) taking control.

Not all women view chemotherapy-induced alopecia as a negative. Lemieux, Maunsell and Provencher (2007), reported that for a minority of women alopecia as a side effect of treatment was viewed as a positive, confirming the efficacy of the chemotherapy. More recently, women have begun to adopt the strategy of total disclosure and expression of individuality by exposing their baldness as a symbol of beauty. Blynn (2003) began her own campaign to encourage women to embrace their cancer journey with an understanding that beauty and femininity come from within. She reported that her decision to expose her bald head after her own cancer treatment was a badge of courage and survival. She stated:

If enough people see a bald head like mine in the context of visual media in which people seek out what is fashionable, then it will engender compassion and acceptance from the public-at-large for women who are so deserving of a big societal hug (baldisbeautiful.org).

1.8. Breast Cancer and Depression and Anxiety

According to a report by Ganz (2008), a prior history of depression and serious life events in the five years preceding the cancer diagnosis were predictive of high levels of distress after breast cancer. Episodes of anxiety and depression are to be expected after a woman receives a diagnosis of breast cancer. It is important to for a woman to understand the difference between what can be managed by coping on her own and what requires professional help.

There are certain signs to be aware of that are consistent with clinical depression such as continuous feelings of sadness, decreased interest and pleasure, feelings of worthlessness and guilt, lack of interest in intimacy and thoughts about suicide (Lange,

1998). The negative consequences of breast cancer and its treatment can cause dramatic changes in relationships and psychological health of both the cancer victim as well as their family members (Badger, Segrin, Dorros, Meek, & Lopez, 2007).

Although anxiety and depression are common in women who have been diagnosed with breast cancer, these disorders are often ignored and left untreated worsening the treatment outcome (Lueboonthavatchai, 2007). Anllo (2000) reported that psychotherapy may be useful in the first few months after diagnosis due to heightened levels of emotional distress.

Other changes identified resulting from breast cancer diagnosis and surgical treatment may consist of insomnia, loss of appetite, inability to concentrate, nightmares, and difficulty returning to work and social activities (Ganz, 2008). Psychological concerns such as infertility, mortality, finances, and family responsibilities are important factors not to be overlooked (Anllo, 2000).

1.9. Breast Cancer and Sense of Self

According to McKay and Fanning (1992), “One of the main factors differentiating humans from other animals is the awareness of self: the ability to form an identity and then attach a value to it” (p. 1). Some aspects of our sense of self may include our self-image, self-perception, self-worth, self-confidence, self-concept, and self-esteem. All of these aspects of self are associated with our own view of who we are as well as how we believe we are perceived by others.

Beatty et al. (2008) found that breast cancer challenges women’s self concept to a point where they did not know who they were anymore. As described below:

Women with breast cancer report difficulties with multiple areas of self-concept, including physical, personal, and social aspects. With regard to

physical self-concept, body image was one of the most frequently mentioned themes by participants in all groups. Almost all patients reported that some aspect of their body image had been challenged by breast cancer, such as feeling unattractive, missing their breasts, feeling 'lopsided', and coping with weight change and hair loss (p. 336).

A meta-synthesis of 30 qualitative research reports published between 1990 and 2003 investigated the effect of breast cancer on a woman's self (Bertero & Wilmoth, 2007). They identified four aspects of the self affected by the diagnosis of breast cancer and its treatment. The first interpretation, awareness of their own mortality, caused these women to go on a psychological journey analyzing accomplishments and reorganizing their priorities in life. While on this journey the women experience fear, sadness and fright leading them to question what was happening to them and the very real possibility of their own death.

The second interpretation, living with an uncertain certainty, describes the only certainty for these women are that they will always be a breast cancer patient as well as the uncertainty of many other aspects of their life. For instance, will they have a recurrence? What would be the quality of their lives? Information and support was said to have reduced some of their uncertainty. Practical and emotional support was key to adjusting to this new situation. This uncertain certainty was explained to have affected both the individual self and the relational self.

The third interpretation, attachment validation, was present in four dimensions described by Bertero and Wilmoth (2007). These four dimensions were identified as, (1) validation by one's own self, (2) their significant other, (3) their family and (4) their healthcare team. This involved a life review and a decision that they were not ready to die. In attachment validation many women focused on self-improvement with a focus on

the inner and physical self. Spiritual reflection helped many to realize that they had value in their lives.

Validation also occurred when the women's significant other demonstrated physical and emotional love. In addition, it was important for the women's family to be understanding and aware of her limitations. And it was essential that the healthcare team recognized these women as individuals and provided empathy. Support, love and respect were the overall needs which, when present, affected the self positively. When these needs were not met and the women were ignored it affected the self negatively.

The remaining interpretation is identified as redefinition of self. Here, Bertero and Wilmoth (2007) described both a physical redefinition and a mental redefinition of self occurring along three lines. The first, body picturing, interprets how the combination of breast surgery and treatment side effects caused some women to report that they were unable to recognize their own bodies. They were described as viewing their bodies as "altered" causing them to feel imperfect and "not normal".

The second, physical functioning caused the women to place less of a value on themselves because they were no longer able to physically manage the things they were once able to do. In some women the physical functioning also disrupted aspects of their sexual intimacy. Decreased feelings of enjoyment during sex as well as loss of fertility as a result of chemotherapy became problematic. Younger women of child bearing years were fearful of being "incomplete women".

The third, womanhood/femaleness, the women had many questions related to self as described as, "Am I still a desirable woman?"; "Am I still a woman even though I don't look like one?"; and "Am I still lovable even though things are different with me

sexually?”

Bertero and Wilmoth (2007) concluded that regardless of a woman’s ethnicity or race, breast cancer affects the self in much the same way. The belief that death may be imminent caused these women to ask more existentialistic questions and prioritize their lives in a way that they no longer focused on the small stuff. Additionally, the importance of attachment validation by both the women’s significant other and the woman, herself, will forever impact her perception of herself.

According to Bertero and Wilmoth, redefining the self caused these women to take a look at themselves before and after their breast cancer diagnosis. A direct quote from their findings:

The dialogue about “who am I now as a woman” that occurred in the women from varying cultures across the multiple studies supports the notion that, at her core, a woman defines the self as female. To the extent that breast cancer alters a women’s perception of herself as female, it threatens the very core of a woman’s psychological framework (p. 200).

Moorey (2007) supported these findings describing body image as an important predictor of sexual self in women with breast cancer. How a woman perceives her partner’s reaction to her diagnosis and treatment of breast cancer can influence not only the marital satisfaction but her own adjustment to the diagnosis. Some women report a negative change in their sexual relationship due to their own shame and fear of rejection by their partner. A more recent study by Karabulut and Erci (2009) also supported the importance of attachment validation and femininity. In their study of 123 married women who underwent mastectomies supporting needs of femininity and body image was statistically significant. They identified that sexual activity involves interpersonal

relationships and that breast cancer can alter both the physical and psychological symbols of femininity in women resulting in decreased feelings of sexuality.

Beatty et al. (2008) substantiated the findings of Bertero and Wilmoth in their qualitative study exploring psychosocial concerns and needs of Australian women diagnosed with breast cancer. They reported that symptoms of fear and anxiety persisted in the participants related to reoccurrence as well as the implications that a reoccurrence might have on their partners and children. Body image, career concerns, physical limitations, and relationship/intimacy echoed as concerns in the study. According to Beatty et al. (2008), "Given that the time of diagnosis and adjuvant treatment are key times for psychological intervention, it is important to identify these needs as early intervention may prevent long term psychological morbidity from occurring" (p. 332).

A qualitative study by Wallace, Harcourt, Rumsey, and Foot (2007) described the unique difficulties presented to adolescent females experiencing cancer such as scarring and disfigurement, permanent limb loss, temporary or permanent hair loss as well as weight loss and gain. Appearance-related side effects were of high concern for these adolescent females, reporting hair loss as the worst part of their treatment, despite other physically painful and uncomfortable side-effects.

A study by Harcourt and Frith (2008) reported that fears about an altered appearance by women diagnosed with breast cancer can be just as consuming as the reality. "It is the outward changes that publicly identified participants as having cancer and as a consequence, presented them with an additional array of potential stressors" (p. 603). An initial randomized controlled study of 27 patients with breast cancer identified alopecia as one of the most difficult side effects of treatment (Titeca, et al., 2006). Lucas

(2004), a breast cancer survivor, stated: “Losing my hair is harder than losing my breast because everyone can see it happening” (p. 77).

A study surveying a random sample of 73 healthy women with severe facial blemishes concluded that facial appearance plays a major role in one’s self-perception as well as their interactions with others (Balkrishnan, et al., 2004). The general consensus held by most cancer patients, in addition to the disease itself, is their concern related to the negative effects cancer can have on their appearance. A woman’s ability to successfully view herself as attractive is an important aspect of going through cancer treatment. This study is a first step toward exploring whether appearance-related changes due to breast cancer treatment manifest into other areas of a woman’s life.

1.10. Self-Esteem

By self-esteem we refer to the evaluation which the individual makes and customarily maintains with regard to himself. It expresses an attitude of approval or disapproval, and indicates the extent to which the individual believes himself to be capable, significant, successful, and worthy. In short, self-esteem is a personal judgment of worthiness that is expressed in the attitudes the individual holds toward himself.

Stanley Coopersmith

Branden (1992) described self-esteem as having internal roots. He stressed the importance of understanding that these roots are in one’s mental operations and not based on external successes or failures. He cautioned that lack of understanding into this principle can lead to anguish and self-doubt. In his work as a psychotherapist, Branden

stressed that self-acceptance and self-responsibility were indispensable to a healthy self-esteem.

Nezu & Nezu (2003) reported, “The way we think and feel about ourselves, our abilities, our self-worth, that is, our self-esteem, can affect the way we think and feel about the future” (p. 2). They concurred that we often fall into a trap of comparing ourselves to others. This self-evaluation by comparison to others can disturb our sense of self resulting in self-doubt and an inability to reach goals. They define one’s spirit as their “vital essence” or “true self”. In order to achieve one’s goals an individual must direct their efforts to discover this true self; otherwise, one can find that their self-esteem is riding a roller coaster of ups and downs. In other words, if one has not identified this true self, their self-esteem can be knocked off balance when certain life situations arise that cause them to compare themselves or their abilities to others. The diagnosis, treatment, and appearance-related side effects of breast cancer are one example of a life situation that can alter one’s self-esteem and cause one to question their established sense of self.

1.11. Physical Attractiveness

“Whether we admit it or not, our appearance really does matter. What was once considered trivial vanity is now seen as a legitimate concern for some people. Maintaining and improving appearance and body image is an important part of our quality of life,” (Hyland, 2008, p. 1). For some women with breast cancer self-worth based on appearance becomes a huge challenge for her self-esteem. To date, it has been well documented that visible facial problems such as scarring, blemishes, disfigurement, facial wasting, etc., have been found to decrease self-esteem, self-confidence, and

promote a negative self-image (Cohen, Cullen, & Martin, 1982; Cash & Pruzinsky, 2002; Sarwer, Pruzinsky, & Cash, 2006; Titeca, et al., 2006; Wallace, et al., 2007).

Bodily impairments can cause as much psychological damage as facial disfigurement according to an experimental study investigating the impact of breast scarring on physical attractiveness (Ogden & Lindridge, 2008). They concluded that women often experience a negative perception of self following breast cancer surgery. Often women compare themselves to others.

Ongoing research into ‘mirror neurons’ tells us that when we relate to another person, they become a mirror that reflects back to us our own vision of ourselves. This network of cortical regions in both monkey and human brains provides this interpersonal coding (Gallese, 2001). If we experience our bodies as negative or lacking, others will then experience us that way. We are just beginning to understand how our brains exist in relationship to other brains (Cozolino, 2006). Breast cancer, therefore, not only poses a threat to the physical health of these women but also to their image of self and how they feel they are being perceived by others.

As clinical social workers we typically work with vulnerable populations. The people who come through our doors generally report a low self-esteem. Self-esteem usually refers to the view and feelings one holds about themselves. One aim of this study is to explore whether women who have received treatment for breast cancer identify any appearance related concern. Does looking good actually help a woman recovering from breast cancer feel better about herself. To what extent do the appearance-related side effects of breast cancer treatment affect social functioning? This study will explore several spheres of interaction including spouse/partner, family, work relations,

recreational and school. Do the appearance-related side effects of breast cancer treatment inhibit one from engaging in social activities? Do these women who are going through appearance-related changes develop schemas about themselves that interfere with their functioning?

The importance of attractiveness for women has been well documented (Bloch & Richins, 2006; Ganz, 2008; Nash, Fieldman, Hussey, Leveque, & Pineau, 2006; Ogden & Lindridge, 2008; Sarwer, et al., 2006; Titeca, et al., 2006; Wallace, et al., 2007). Research has repeatedly shown that knowledge of the benefits of attractiveness are shared by the general public resulting in billions of dollars spent annually on appearance-enhancing products (Bloch & Richins, 2006). Researchers have discovered that the attribute of physical attractiveness can indeed influence positive job outcomes (Poon, 2000). Sarwer et al. (2008) stated, “there is now a large body of research that has developed since the 1970’s that shows the situation across the lifespan, that more attractive people are seen in a more favorable light and are also treated more positively than other people” (p. 3).

Numerous studies have shown the extent to which self-perception of physical appearance can influence one’s psychological state (Cash & Pruzinsky, 2002; Maltz, 1960; Roizen & Oz, 2009; Sarwer, et al., 2006). This study will explore whether assumptions play a role in women dealing with appearance-related side effects of breast cancer and whether assumptions affect their social functioning.

A study by Nash, Fieldman, Hussey, Leveque and Pineau (2006) concluded that using make-up had a beneficial impact upon the perception of many aspects of a woman’s life which included her confidence, earning potential, health, and professional class. Their results from web-based questionnaires suggested that women employing

cosmetics to manipulate appearance may benefit from a boost in their self-perception and well-being.

Ettcoff (1999) described appearance as “the most public part of the self” (p. 7). Throughout history women have attempted to alter their appearance through piercing, tattooing, tweezing, painting, cutting and burning different parts of their bodies. Although seemingly shallow, our attraction to beauty is based in reality (Roizen & Oz, 2008). What is known as the ‘attractiveness halo’ appears to occur cross-culturally, ascribing a list of positive traits to those who are found to be more physically attractive. According to Ettcoff (1999), these expectations start in childhood with teachers ascribing intelligence and popularity to good looking students. Ettcoff reported (p. 48):

Teachers in four hundred classrooms in Missouri were given a report card of a fifth-grade student, including grades, evaluation of attitude, work habits, and attendance. The only variant was the attached photograph of the child, an attractive or unattractive boy or girl. Despite the wealth of information about behavior and performance, looks swayed opinions.

Further, according to Shanon and Stark (2003), numerous research findings support the notion that attractive individuals have an advantage in the job market. Physically attractive men and women are more likely to be hired, promoted, and receive higher salaries (Ettcoff, 1999).

According to Cash and Pruzinsky (2002) sociocultural perspective focuses on how our cultural values influence and shape our individual values and behaviors. This approach to human behavior is said to be important in understanding how we develop our perceptions of self and the perception we have of others. For instance, in our western culture the importance of physical attractiveness is high on the rating scale; therefore,

individuals in our western culture will value this quality for themselves and for others (Cash & Pruzinsky, 2002).

Sarwer et al. (2006) elaborated on Darwin's conceptualization of natural selection when tracing the roots of the earliest discussions of the importance of physical attractiveness. According to the natural selection theory, survival and successful reproduction is the primary goal of all species. In order to achieve this goal a mate must be identified who can successfully contribute to reproduction. "Through natural selection, specific physical characteristics have evolved in ways to signal an animal's (or human's) reproductive availability" (p. 23). These characteristics become the foundation for what is considered attractive.

During adolescence, females become more preoccupied with their appearance and how they will be perceived by both their male and female friends. The struggle to "fit in" is an important aspect of their sense of self. As girls begin to develop women's bodies during adolescence they are said to dissociate from their own body hungers and instead internalize a "male gaze" (Tolman, Impett, & Tracy, 2006). Wallace et al. (2007) described altered appearance in adolescent female cancer patients as an enormous concern. They report that this altered appearance can have an impact on self-esteem as well as social interaction with peers. Carr (2008) described appearance related changes of cancer treatment as visual clues that point out the illness. She compared these changes to wearing a scarlet letter "C".

To understand the impact altered appearance from cancer treatment can have on self-esteem it is important to use methods to uncover the rich descriptions from real

people. This study assumes the importance of looking like oneself throughout the cancer journey. This study, therefore, gathered the data from the women themselves.

There is a need for research in the area of appearance-related side effects of breast cancer treatment to underpin an appropriate method of support and intervention for women who are dealing with these issues. This is an aspect that has been largely overlooked in existing breast cancer research in the United States despite the acknowledgement of the problem. As clinical social workers and psychotherapists, this study can help us to better understand the needs these women may have related to embodiment, improving their overall sense of self, both inside and out. Ultimately, this information can lead to evidence-based interventions to help these women approach their diagnosis and treatment with improved coping strategies, symptom reduction, and greater confidence.

The advancement of clinical social work knowledge requires not only that we look at the inner working of the mind but the embodiment of the self. According to Cash and Pruzinski (2002), “The experience of embodiment is central to the quality of human life” (p. 516). We need to challenge the notion that altering one’s appearance is controversial. This requires that we open the door to change. By recognizing that there is a need to address appearance-related issues with women who are receiving treatment for breast cancer social workers can learn to validate these women’s feelings and build a resource base to address their needs. When we fail to pay attention to these issues we continue to deny that they exist. Harcourt and Frith (2008) concluded that one aspect that was clear with women who had been diagnosed and receiving treatment for breast cancer

was that they worried about the possible changes to their appearance even before they occurred. They suggested that (p. 604):

Those providing care and support for people who are about to embark on (or who are currently undergoing) treatment that will alter their appearance (if only for a relatively short period of time) should also be aware of the impact this can have on the individuals concerned. Attempts should be made to facilitate the discussion of appearance-related issues with women who are undergoing chemotherapy treatment in order that concerns about an altered appearance can be aired and appropriate supports made available, if necessary before those changes take place.

The future of science and social work practice related to altered appearance depends on the willingness to assess these aspects of breast cancer treatment.

1.12. Breast Cancer and Social Functioning

Throughout history addressing social functioning has been an important aspect of social work as a profession. The National Association of Social Workers (2010, pp. 1-2) provides the definition below:

Clinical social work shares with all social work practice the goal of enhancement and maintenance of psychosocial functioning of individuals, families, and small groups. Clinical social work practice is the professional application of social work theory and methods to the treatment and prevention of psychosocial dysfunction, disability, or impairment including emotional and mental disorders. It is based on knowledge of one or more theories of human development within a psychosocial context

The perspective of person in situation is central to clinical social work practice. Clinical social work includes interventions directed to interpersonal interactions, intrapsychic dynamics, and life support and management issues. Clinical social work services consist of assessment, diagnosis, treatment, including psychotherapy and counseling, client-centered advocacy, consultation, and evaluation.

Women function in many different roles in society, for example, as a parent, spouse, employee, employer, etc. Bourjolly, Kerson, & Nuamah (1999) identified social functioning roles in women with breast cancer to include household, family, social and

community, self-care, and occupational activities. Social functioning has been defined as “normative behavior in a social situation” (Blakely & Dziadosz, 2007). Frierson and Andersen (2006) reported that women’s responses to her breast change must be considered in the context of “psychological adjustment, social adjustment, relationships with sexual partners, physical symptoms, and related concerns” (p. 173). They noted that a high incidence of sexual disruption may prompt concern related to disruptions in marriages. Further concerns related to a cancer history included financial difficulties, narrowing of employment options as well as the concerns related to health care coverage.

The need to form interpersonal connections and function in society is described as one of our most fundamental human motivations (Murray, Rose, & Griffin, 2003).

Breast cancer diagnosis can lead to impairment in many areas of a woman’s life, including her social functioning. Women with appearance-related side effects of cancer treatment may become preoccupied with their appearance and with possible negative reactions by others in society. Bandura (1986) proposed that social functioning depends on how the individual interprets the results of their behavior and alters their behavior to fit societal expectations.

Social changes resulting from appearance-related breast cancer treatment are potentially disrupting. Visible facial problems can lead to avoidance of social situations. Women with altered appearance related to breast cancer treatment have changed their plans, kept away from social settings, and avoided shopping, gardening, and even answering the door because they didn’t want to be viewed by others as looking different (Harcourt & Frith, 2008). Bourjolly, Kerson, & Nuamah (1999) reported that, “social functioning was better if women did not use escape-avoidance coping, feel as though

their breast cancer held them back from doing what they wanted to do, or was a threat to their self-esteem” (p. 16).

Women in treatment for breast cancer have reported dissatisfaction with body-image as well as difficulty in sexuality and sexual functioning (Fobair, Stewart, Chang, D’Onofrio, Banks, & Bloom, 2005; Schover, 1994). Body image has been identified as a component of a larger concept of self that relates to femininity and womanhood. Most breast cancer survivors continue to report difficulty in areas of sexuality for up to three years post diagnosis (Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998). Surgery, chemotherapy, and hormonal therapy are some contributing factors impacting sexuality. Chemotherapy can result in ovarian failure leading to premature menopause for young women (Anllo, 2000).

In sum, chapter one provided the reader with current breast cancer statistics as well as the description of various treatment options. This chapter identified side effects of those treatment options as they related to altered appearance in women with breast cancer. Finally, this chapter cited several studies related to self-esteem, body-image, and attractiveness and how a negative perception of self can affect psychological and social adjustment in women undergoing treatment for breast cancer.

CHAPTER 2

Theoretical Orientation

2.1. Theories Related to Self

According to Bertero and Wilmoth (2007), there is no universally accepted definition of self. The self is comprised of one's perceptions, thoughts and beliefs about oneself as well as how one is perceived by others. In their work with women and breast cancer they describe three basic representations of self, the individual self, the collective self, and the relational self. These three representations have to do with differentiating oneself from others, relationship with others and inclusion in groups. They have found that women with breast cancer struggle to redefine themselves, often perceiving that they are not complete women. Breast cancer can be viewed as an assault on the self leaving these women to begin a self-reflexive process (Bertero & Wilmoth, 2007). A diagnosis of breast cancer directly alters a woman's sense of self. In return, this altered sense of self directly affects one's self-esteem.

Likewise, a study by Leary, Terdal, Tambor, and Downs (1995) confirmed the importance of the relational self. They explained the self-esteem motive:

The most widely acknowledged explanation is that people strive for self-esteem because high self-esteem promotes positive affect by buffering the person against stress and other negative emotions and by enhancing personal adjustment, whereas low self-esteem is associated with depression, anxiety, and maladjustment (p. 518).

In an effort to clarify the undisputed link between self-esteem, affect adjustment, and health, the authors offer three sets of explanations. First, "because self-esteem is associated with confidence and high expectations of success, high self-esteem is associated with optimism and lowered anxiety" (p. 518). Second, high self-esteem

promotes goal achievement. People will strive toward their goals despite obstacles.

Lastly, it is suggested that people seek self-esteem for its own sake, to maintain a sense of integrity or adequacy.

Leary et al. (1995) emphasized one's need for inclusion in a group. The hypothesis of their study was that self-esteem function acts as a sociometer to monitor whether the individual is being included or excluded by others; ultimately, causing the individual to adjust their behaviors to avoid rejection by others. They explained that psychological systems evolved to motivate individuals to develop social relationships and groups as a way of survival and reproduction.

In a study by Murray, Rose, and Griffin (2003) using the basic tenets of the sociometer model of self-esteem, it was determined that married partners who felt more positively regarded perceived greater acceptance and love. Their longitudinal study also revealed that people who felt less positively regarded by their partner internalized acute experiences of rejection.

2.2. Psycho-Cybernetics

Maltz (1960) introduced his analogy of goal visualization. Maltz was responsible for popularizing the term "self-image". He believed that each of us carry with us a mental blueprint of ourselves. This blueprint is based on our self-image. This self-image is built up from our belief about ourselves. These beliefs can be formed by our successes as well as our failures. They can be based on how we view ourselves and how others have reacted to us. Social factors, indeed, contribute to the personality development of the individual.

Today, our sense of self may be a cumulative result of judgments related to our appearance, academic achievements, social skills, physical challenges and so on.

According to Leary et al. (1995), practically everyone cares about what people think of them including those who insist they are not affected by others opinions.

Maltz (1960) believed that everyone has the ability to change ones self-image. He insists, however, that positive thinking isn't enough when focusing on our goals. We have to change our self-image by changing both our outer appearance as well as our thinking of the "self". This concept is consistent with cognitive theory. Utilizing an automatic thought record can help an individual to challenge and restructure negative distortions. Psycho-Cybernetics takes the cognitive behavioral approach a step further realizing that it is not enough to change this thinking without believing in the "self" to follow through. By self, Maltz refers to the conscious reflection of one's own being or identity.

To relate this to altered appearance, we must understand that women are social in nature. Their identity is influenced by their interactions with others in society. The very visible signs of cancer are enough to change this self-image based on society's reaction.

2.3. Interpersonal Theory

Many theories have arisen over the years related to self-esteem and self-perception. Sullivan (1953) explored the importance of how one perceives oneself and how they are perceived by others. His concept was that the self was "based on an interactive, mutual influencing process in which the individual is constantly adapting to the environment, learning by and attending to the linguistic and bodily cues delivered by others" (Cushman, 1995, p. 177). Our very self, according to Sullivan's theory, is motivated by our need for security. This security need is met when our interaction with

others do not produce feelings of anxiety or depression. He described the self as the “primary and most important element of the person” (Cushman, 1995, p. 270).

Several neurobiological studies have contributed to the understanding of brain functioning and perception. The foundational theory of interpersonal neurobiology describes our brain as a social organ that is built through our experiences with others. According to Cozolino (2006), the human brain exists in relationship to other brains. Our own brains develop in the context of our relationships. Our relationships have the power to reshape our brains throughout life. Sometimes the brain shaping can become disordered by a negative event, such as breast cancer. Healing interactions, which can be identified as acceptance by others, can trigger changes in our brains which can help them grow in positive ways and if, and when, the conditions are right, heal suffering through these neural changes known as plasticity (Cozolino, 2002).

What is known as the “mirror neuron system” clarifies the profoundly social nature of the human brain. This system reveals how the brain is able to perceive the expressions of other individuals creating an internal state that resonates with that other person (Siegel, 2007). Therefore, first impressions can be lasting ones. Women diagnosed with breast cancer report side effects contributing to how they perceive themselves and fear of how they may be perceived by others. If women who are in treatment for breast cancer can feel better about themselves through techniques that can help them to prepare for the devastating side effects of cancer treatment, then they may very well project this more confident sense of self to others.

How we perceive ourselves and how we are perceived by others is central to our development and existence. One of the problems is that perceptions of self can be based

on truths or one's imagination. These perceptions can be built by false messages given to us by our parents, our teachers, our friends, the media, or by our own distorted thinking.

Accordingly, women struggling with the side effects of breast cancer may be at risk for losing their very sense of perception of self based on these false messages, also known as "assumptions."

2.4. Cognitive Theory

We are disturbed not so much by the events but by the views which we take of them.

Epictetus, Greek philosopher (55AD-135AD)

It has been written that the origins of cognitive theory date as far back as the first century A.D. During the 1950's Wolpe (1988) shook up the therapeutic community with his theory on patients who suffered from fears. He minimized Freud's drive theory when he reasoned that an irrational fear of something could very well be the "whole phobia". Wolpe hypothesized that if a fear could be removed, it would ultimately extinguish the phobia.

Drawing on the same conclusion almost a decade later, Albert Ellis developed a cognitive approach to depression known as Rational Emotive Therapy (RET). Rational Emotive Therapy was found to be more highly effective in obtaining significantly better results with his clients (Ellis & Harper, 1961). This theory was based on the belief that the human being is normally kind and loving to other human beings. However, when one becomes enmeshed in illogical thinking, this can lead to self-destructive behavior. Ellis and Harper (1961) further hypothesized that this irrational thinking can be exacerbated by one's culture. These early years of formation are highly influenced by family and social

pressures. Many of the irrational “self-sentences” can come from parents, teachers, peer groups, contact with the general culture, and the mass media. According to Ellis, to understand a person’s behavior, we must first understand how people perceive, think, emote, and act (Ellis & Harper, 1961).

Following on the same path, Beck (1979) trained as a psychoanalyst, began to question Freud’s theories. Beck agreed with Ellis, that emotion comes from what we think. He believed that if an individual can identify and change their habits of thought this could relieve their symptoms of depression. Simply stated, that if the thoughts can be changed, the feelings will change. This led Beck to conceptualize what are known as “cognitive schemas”. In his observations with depressed patients Beck concluded that an individual’s schema consisted of three basic themes of personal ineffectiveness, personal degradation, and viewing the world as an unpleasant place (Walsh, 2006). These schemas are defined by Young (1990) as “extremely stable and enduring themes that develop during childhood and are elaborated on throughout an individual’s lifetime” (p 9). This concept of schema helps the individual to understand their own cognitive representation of past experiences with people and situations and how these past experiences may continue to distort present situations. Moorey (2007) described that there are schema’s for all aspects of an individuals life but the most emotionally salient are known as “self schemas”. He reported:

These schemas are likely to be activated in certain situations where the body is likely to be exposed to the gaze of self or others, such as trying on clothes, wearing a bathing costume or having sex. If the body image is basically positive there may be no difficulty in these settings, but when a negative body schema is present a set of negative thoughts will ensue, such as, “I look awful, I’m too fat, and I’m ugly.” These will be accompanied by negative affect – shame or disgust. This self-critical attitude may then lead on to actions to reduce the sense of shame of

exposure, such as avoiding situations where the body is exposed, wearing loose fitting clothing or making love in the dark (p. 74).

Cognitive theory asserts that human behavior and emotional experiences are rooted in conscious thinking (Walsh, 2006). According to Walsh, “Cognitive theory postulates that we develop habits of thinking that form the basis for our screening and coding of environmental input, categorizing and evaluating experience, and judgment about how to behave” (p. 132). Moorey (2007) concluded that, “Cognitive behavioral models of body image emphasize how negative schemas become activated when there is a change in body appearance through illness or disfigurement” (p. 85). Cognitive therapy, a reality-based intervention, can help an individual accept their life situation while focusing on the assumptions which they hold about themselves, often preventing them from generating active solutions (Freeman & Dattilio, 1992). How a woman feels about herself throughout her cancer journey can impact how she functions in various social roles in her life.

2.5. Status Generalization Theory

According to Jackson (2002), status generalization theory, which evolved from two sociological theories known as expectation states theory and status characteristics theory, focuses on how external status characteristics influence social interactions. This theory states that society discriminates among individuals who do not meet societal expectations and establishes performance expectancies based on appearance. Jackson (2002) reported that not only are people judged by their physical appearance but society behaves differently toward them as a result. This is consistent with the results of a study by Ogden and Lindridge (2008) which explored whether scarring following a lumpectomy generated negative judgments. Their study found lower ratings of

attractiveness and self-esteem confirming some women's assumptions that they will be judged more harshly following breast cancer surgery.

In sum, this Chapter presented a description of theories related to one's sense of self, which include, but are not limited to, self-esteem and self-image. This chapter began by laying the foundation for the theoretical framework. The chapter described how social factors play a role in personality development. Interpersonal theory describes how one's sense of self can be affected by their interactions and approval or disapproval from society. Cognitive theory is woven into this framework to describe how one's assumptions and false beliefs related to physical appearance can affect their social interactions. Additionally, information related to neurobiology and interpersonal experience was explained to develop an understanding of brain functioning and how it connects to these theories. This chapter attempted to make the connection between altered appearance related to breast cancer treatment and how it may affect one's perception of self as well as how one feels they are being perceived by others.

CHAPTER 3

Methods

3.1. Research Questions

The purpose of this study was to explore and describe the appearance-related issues of breast cancer treatment on a woman's sense of self, self-esteem, and social functioning by interviewing the women themselves. This chapter presents the methodology used in this exploratory, descriptive study. Information in this chapter will include problem statement, sampling and recruitment, data collection, and human subjects risk/benefit assessment. Through the use of qualitative descriptive methods (Denzin & Lincoln, 2005, Morse, 1994; Padgett, 2008; Thorne, 2008), we can bring phenomena to the awareness of our colleagues as a first step in creating an empirical basis for generating additional questions related to those phenomena. The term "description" in this research study is used for the purpose of telling what has been observed (Sandelowski, 2000).

The research aim was to elicit participants' views of their breast cancer journey by having the women tell their own stories. These stories included personal experiences, feelings, and concerns as the women described the appearance-related aspects of breast cancer treatment and whether it impacted their sense of self, self-esteem, and social functioning. The study described and reported to the reader what was heard from the participants. This study built the findings based on inductive reasoning with the hope of bringing phenomena to the awareness of clinical social workers (Thorne, 2008). The purpose of the study was to explore the following issues:

- 1) Of the participants, did appearance-related issues affect their overall sense of self.
- 2) How did the women interviewed feel about their self-esteem prior to, during, and following their treatment for breast cancer?
- 3) To what extent did the appearance-related issues interfere with the women's overall social functioning which may have included shopping, social events, sexual intimacy, and spiritual activities?
- 4) Were assumptions involved related to appearance-related changes?

3.2. Research Design

This study utilized a qualitative descriptive research method consisting of semi-structured in-depth interviews using a prepared interview guide (Appendix D). Open-ended questions and probes were used directed at eliciting responses from a number of women who had been diagnosed with breast cancer and had received treatment which may have resulted in appearance-related issues. Questions were made open-ended to avoid leading the participant. The interviews were audio-recorded. They were transcribed using the raw data which included word-for-word quotations of the participant's responses. Notes were also used to recall comments and treatments that were unclear on the tape. The data was analyzed identifying major themes common to all participants. These open-ended interview questions were used to encourage the women to describe any appearance-related changes of breast cancer treatment and how these changes may have affected their sense of self, self-esteem, and social functioning.

3.3. Selection Criteria

Participants were selected because they were representative of the same experience, receiving treatment for breast cancer (Morse, 1994). The initial plan was to conduct 15-25 interviews; however, theme saturation was reached after twelve interviews with no new data forthcoming. This total of N=12 women met the inclusion criteria of being over the age of 18, English speaking, and had received treatment for breast cancer. This purposeful selection of participants ensured gaining access to the details of their individual lived experiences.

3.4. Instrumentation

An in depth, open-ended interview guide (Appendix D) was developed for this study to elicit responses related to the aims of the study. This interview guide was comprised of 27 questions and probes designed to understand appearance-related issues. A survey was also developed to collect background demographic data.

3.5. Recruitment

Purposive sampling included 12 female breast cancer patients who were introspective and able to provide descriptions of their breast cancer treatment experience. The sample was comprised of women who had received treatment for breast cancer in metropolitan and rural areas of Philadelphia (Southeast Region), New Jersey, Delaware, and Chicago that serve a range of socioeconomic statuses as well as a range of cultural diversity and sexual minorities.

Participants were recruited through postings of an IRB approved flyer (Appendix A). This flyer was created and distributed to a network of providers of breast cancer services, such as physicians and hospitals asking them to post it in their office. The flyer was also posted on the bulletin board of local supermarkets describing the research study

and asking for voluntary participants. In addition, the flyer was posted on the doors of two private practice offices, which provide mental health services in the suburbs of Philadelphia.

Participants were screened through a telephone interview to determine if they met inclusion criteria. Further explanation of the study and any questions the respondents may have had related to the study were answered at this time. An interview was then arranged either in person or via telephone at a time and place that was most convenient for the participant. The interviews ultimately took place in one of the two private mental health offices in the suburbs of Philadelphia. After receiving consent (Appendix B) and the background survey on demographic data (Appendix C), participants were interviewed individually with the interview lasting approximately 30 to 60 minutes. Participants were asked if they could be contacted in the future to read what was written about them (member checking) (Okta, 2005) and determine if it seemed plausible to them. Subjects were made aware that they could withdraw from the study at any point and for any reason.

3.6. Data Collection

All interviews were collected between October 2009 and January 2010. All data collected was kept confidential. The confidential background surveys were kept in a locked file cabinet. The audiotapes were transcribed by a professional legal secretary who understood and abided by client confidentiality. This legal secretary was provided only with the coded tapes and no other identifiable information. To continue to assure anonymity and confidentiality the audiotapes have been erased following transcription. The transcripts were secure in a separate locked file cabinet in the same office to ensure

that they could not be connected to any information related to background demographics. The anonymity of all of the participants was protected in presentation of the findings.

3.7. Data Analysis

The data was qualitatively analyzed to determine whether the participants experienced appearance-related issues of breast cancer treatment. If so, how did these issues impact the women's sense of self, self-esteem, and social functioning? Were assumptions involved in impacting any of these areas? The analysis of findings used the four stages outlined by Morse and Field (1996). These four stages involve: comprehending, synthesizing, theorizing, and recontextualisation.

First, during the comprehending stage, the transcripts were read and re-read to retrieve all comments made by the participants and become familiar with the data. Marking was done by bracketing passages of transcript that held meaning. This line by line analysis of each interview transcript was done to identify labels and make sense of the data. Memo writing was used to record comments and thoughts. Persistent words and phrases were noted. Codes were then developed, assigning units of meaning to the data.

Two methods were used, described in First Cycle coding outlined by Saldana (2009) to help to manage the data. These methods consisted of "attribute coding", a notation at the beginning of the data providing a basic description of participant's characteristics such as age, occupation, diagnosis, etc. A method of "emotion coding" was used to describe human emotion, such as, anxiety, uncertainty, self-consciousness, etc.

During the synthesizing stage the information was organized by sifting data into a pattern during which norms, ranges, and variations began to emerge. This was done by cutting segments of transcript with the sub-concepts, emerging themes, and commonalities and placing them into folders, taking all of these parts of data to form the whole. This process led to theorizing, moving the sub-concepts to a higher level of abstraction to develop the initial concepts. During the recontextualizing stage theory began to link findings with the literature in Chapter 2 related to both interpersonal and cognitive theories.

A method from Second Cycle coding known as Focused Coding, was used to merge similar codes together (Saldana, 2009). For instance, ‘annoyance’ and ‘anxiety’ became persistent emotional codes when strangers approached cancer patients in public. A unit of meaning assigned to this data was “perceived as a cancer patient” and “stigmatized”. When using what cognitive behavioral therapists refer to as the “Colombo” approach to questioning, such as asking, “So what”, or “Tell me more”, the data began to lead to new discoveries and take on a more abstract meaning. Morse (1994) described this process as piecing together the data through astute questioning. In this case, the theme that emerged was ‘violation of boundaries by strangers’. The heading encapsulated both positive and negative emotional codes related to overstepping boundaries.

To help corroborate the findings, reduce bias, and look to achieve inter-rater reliability, several devices were employed. A colleague, who is a Psy.D., Licensed Psychologist, was recruited to be a “second set of eyes”. This colleague agreed to code a sub-sample of the transcripts. The colleague had previously not done qualitative coding

and was given a brief overview of the four stages of the coding process as described by Morse and Field (1996). She was then briefed about the study. The colleague chose three transcripts from a pile of twelve to develop her own themes based on what she was reading to determine transferability of the findings. This colleague had no prior knowledge of the study, other than the posted flyer on the door of the office. The colleague agreed to analyze the interviews by doing open coding. The colleague used line by line and “emotional coding” to arrive at the themes.

This colleague described her process of marking and bracketing certain passages in the interviews that seemed to be interesting in relation to the study. Next, a label was given to the marked passages that provided meaning to the data. The codes were then sorted together to form initial concepts. Upon completion of her coding, a discussion took place to compare themes as they related to the study’s variables. An executive decision was made that, although not exact, the themes were similar.

Member checking was done by a colleague in order to help the women to feel less pressured and more open to agree or disagree with the codes that were developed. Verification was sought from the study participants by randomly choosing five of the interviewees and placing phone calls to them to determine if what was captured and described in the interviews was what was intended by the interviewee and that the themes generated from the interviews were valid. No conflicting perspectives or disagreements were identified. Oktay (2005), described member checking as one of the most important devices to ensure trustworthiness.

3.8. Compensation

Participants were given a ten dollar (\$10.00) gift certificate to either Borders or Barnes & Noble Bookstore.

3.9. Human Subjects – Risk/Benefit Assessment

Benefits of participating. This study allowed the participants to process and validates their feelings related to their issues with altered appearance as it pertained to their breast cancer treatment. Their answers assisted in gathering data that was useful in understanding whether appearance-related side effects of breast cancer treatment affect a woman’s sense of self, self-esteem, and social functioning. Further, the study helped to gain a better understanding of the assumptions these women have in regards to their appearance during their cancer treatment.

Risks of participating. There were no known risks of participating in this study. A potential risk may have involved the psychological discomfort of discussing the diagnosis of breast cancer and the appearance related side effects of treatment. The women did not report feeling any discomfort at any time, causing them to stop the interview. All identifying information was stored separately from the individual data in locked files.

3.10. Confidentiality

The participants were made aware that the information they shared was kept confidential. Anything with their name on it, such as consent forms, or any other document that could be used to identify them, was kept in a locked file cabinet, separate from their interview tapes and transcripts of those tapes. The information was strictly used for the purpose of this research study.

3.11. Informed consent

Consent forms met approval by the IRB, following all of the necessary guidelines to conduct this study. The consent forms were read and signed by the research participant after they were screened and agreed to voluntarily participate in the research study.

3.12. Reflexivity Statement

Over the past decade I've had several close friends who have been diagnosed and survived breast cancer. I'm not so sure I truly understood the impact this disease had on many aspects of their lives until I began this research study. To sit in my office and listen while the participants chronicled their stories was heartbreaking. I had to remind myself that these were survivor stories. These women had made it; although I couldn't help to wonder what lies ahead for them. I felt sad and helpless.

My feelings of helplessness took me back many years to a time when my younger sister was in a car accident and had her forehead ripped off. She had hit the windshield of a car but didn't go through it, instead it took her forehead. The surgeon had to graft skin from her buttocks to cover the area. I can still remember the blood curdling screams as I sat in the waiting room of the doctor's office. He had just removed the bandages. The tears ran down my face and I remember thinking I would change places with her in a minute just to take her pain away.

As the days, and weeks, and years went by my sister's life took many turns. She was in a downward spiral. She became isolative and withdrawn. She dropped out of college and sunk into a depression. She never was quite the same. Over the years she had a series of painful surgeries to minimize the graft. She had tissue expanders to stretch the skin every few years. She had her hair cut into bangs and began to wear make-up to cover the scar. At first glance, no one would have known that she was

disfigured. I can still remember everyone telling her how beautiful she looked and I couldn't understand why she couldn't move forward with her life. What I didn't realize at the time was that her scars were much deeper than anyone could see. They were her private psychological scars.

Today, as a psychotherapist, I am much more aware of the psychological scars that people carry. This research study brought with it feelings of guilt, pain, and sadness. It reminded me that it's not about appearance; it's about our sense of self. As a young woman I wasn't aware of the need to validate my sister's feelings. Because she is a beautiful woman everyone just took for granted that she should "get over it".

Interestingly, in one of the interview, a lesbian participant was describing her anger, disappointment and sadness due her botched breast surgery. She described how awful her breasts turned out and asked if I wanted to see them. Because we were taping and I was caught off guard I didn't respond at that moment and she kept talking. Later, after the interview was over she again asked if I wanted to see her breasts. Without waiting for an answer she pulled up her top exposing her scarred and disfigured breasts. I remember feeling shocked, angry, and saddened at what I witnessed. I instantly knew she needed validation. I remembered reading, as reported by Fobair et al. (2002), that "lesbians were significantly more comfortable in showing their bodies to others both prior to and following breast cancer" (p. 427). My sadness was gently verbalized in the words, "I'm so sorry". We sat quietly for a while feeling connected in that moment by our feelings of sadness, anger and shock.

When I realized what was happening in these interviews and how it was triggering my humanness, I didn't feel the need to "fix". I was able to validate and be

present in that moment. My own mindfulness meditation practice has helped me to remain in the moment and know that there is a reason I am doing this research study.

In summary, Chapter three covered methods of the study beginning with the research question. The research design, its implementation, and data analysis were detailed to identify the main approaches and ensure trustworthiness and credibility. This chapter provided the risk/benefit assessment for human subject research and ended with a reflexivity statement.

CHAPTER 4

Findings

A total of 12 women were interviewed. Of the twelve women, all were employed at the time of their diagnosis of breast cancer. The mean age was 52.4 years, ranging from 41 to 65 years of age. The mean age at the time of the breast cancer diagnosis was 45.6 years, ranging from 35 to 52 years of age. Four of the twelve women reported a family history of breast cancer. All of the women were high school graduates, seven were college graduates, and five had completed Graduate School (see Appendix E - Participants' Portrait).

Several key themes emerged as a result of analyzing the data. The following sections focus on the women's accounts of how the appearance-related issues of breast cancer treatment affected their sense of self, self-esteem, and social functioning. For the purpose of this study self was described to the women as how one views oneself or their self-concept, which included self-image and body-image. The term self-esteem was described as how one feels about oneself. And lastly, social functioning was explained to the women as how well they were able to function in their role in society (such as wife, mother, employee, etc.) as a result of appearance-related changes. A list of these themes and sub-themes is as follows:

1. Changes in self-concept due to changes in appearance

Sub-themes:

- 1a. Losing hair is traumatic – not feeling feminine
- 1b. Scarring, tattoos, and body changes – feeling imperfect/not normal
- 1c. Feelings of depression / anxiety

1d. Unprepared for some of the appearance-related changes

2. Changes in social functioning and social network, such as work and other activities

Sub-themes:

2a. Disruptions – physical functioning – womanhood / femaleness (impact on social functioning)

2b. Importance of support network to help with social functioning, emotional support, and self-esteem

2c. Crossed boundaries – both positive and negative in terms of support

3. Advocacy and empowerment

Sub-themes:

3a. Finding a voice

3b. Light at the end of the tunnel

3c. Gained sense of control

Self-esteem, a very critical variable, was at the root of each theme and sub-theme. The threads of self-esteem were tightly interwoven throughout these other variables, sense of self and social functioning. Throughout the interviews it became obvious that appearance-related side effects of breast cancer treatment took the participants on a roller coaster ride related to their self-esteem. These threads of self-esteem quickly became unraveled throughout the breast cancer journey as discussed in the themes below. Themes are illustrated by verbatim quotes from the interviews. Names used in reporting this research data are pseudonyms.

4.1. Changes in self-concept due to changes in appearance

One of the women described the appearance-related changes to her body as “the new normal”. Many of the women described just wanting to go back to looking like themselves, the self that they created. They described that losing hair on both their head and body left them unrecognizable to themselves. These personal changes resulting from breast cancer treatment were described as being traumatic to the women’s established sense of self and self-esteem often causing it to plummet. The women described just wanting to look “normal”. In this first theme several of the sub themes are interwoven throughout. As recounted below:

Tara: Obviously, having a mastectomy and losing your breast, and having reconstruction, um, I felt, obviously, it wasn’t me, I felt, um, I felt lots of people who knew what had happened were looking at me in a different way. (1b)

Betty: Well, I think breast cancer victims need all the support they can get. And one of the areas to support is appearance, to help them look the way they want to look. Not necessarily all made up for whatever, but the way each individual woman would like to look.

Jane: I was, it was much. I just felt very unattractive and I didn’t feel feminine and, um, everybody I looked at I thought just looked prettier and healthier and it reminded me that I had cancer and it could come back and I felt horrible about myself. Um, people would come up and tell me how strong I was and how pretty you look and I never believed it. Because, first of all, you don’t know how strong you are. I didn’t really have much of a choice. I mean, what are you going to do? You have cancer and you need to get treatment. I didn’t feel like I did anything heroic, I just, you know, was treated. And, um, okay, I didn’t, you know, maybe I didn’t look, um, you know, as unattractive to other people as I thought I did. But, you know, clearly they’re kind of trying to make me feel good because, you know, you’re wearing a wig. How great can you look, you know? (1a,b,c,d)

Jane detailed a time when she was feeling self-conscious in the supermarket:

Jane: I remember being in the check-out, this is vivid. At ***** and the checker was, when I was talking to her she wasn’t like looking me in the eye. I could see her looking up at my part where the wig was and I’m thinking, oh God did my wig move or is it up too far and she sees....., like stubble? And I just couldn’t wait to get out of there so I could look in the mirror to see if I had to adjust my wig. And I simply remember just crying in the car over that. Um, and as I remember,

nothing was moved. It was just she was looking at the part, probably trying to figure out is that her hair or is that a wig. (1a,b,c,d)

Losing one's hair was described as the worst part of breast cancer treatment.

Eleven of the twelve women described losing their hair as the worst issue they had during their cancer journey. The twelfth woman did not lose her hair because she had radiation therapy and no chemotherapy treatment. One of the women described her hair loss as, "worse than the breast cancer itself". Another woman stated that her hair loss was worse than any of the surgeries.

Jane: I didn't shop as much. I avoided parties. Um, just going out with friends, I avoided a lot of that. Again, that wasn't due to the physical changes, that was due to the hair. (1a)

Karen: Well, you know, of course, losing my hair was probably as traumatic as having my breast removed. So, that was very difficult, losing my hair. (1a)

Susan: The hair loss was devastating and my self-esteem went in the toilet until I got my hair back. (1a)

Tara: Um, self-esteem, I think when you have cancer and you lose your hair and you feel horrible and you look horrible and you're pale, dark rims under my eyes. I wasn't sleeping. I just, I was very conscious and when I started losing my hair, I didn't want to leave the house. (1a,b,c,d)

Many of the women eventually dealt with losing their hair by cutting it off, wearing wigs, baseball caps, scarves, and turbans. Kathy, a 42-year old woman details her hair experience below:

Kathy: Um, I don't know. I mean, I, um, think I've handled it pretty well, quite honestly. It's a little unnerving when you're bald, that was, that was, a shock. Um, I think of anything that was probably the part that I didn't think was going to be as big of a deal as it was. Um, you know there is a like a 90 something or other percent chance that you're going to lose your hair and like, yeah, you really probably are. And then when it happens and it starts to come out that's something that you're just not ready for. Um, I had really long hair, longer than yours actually, it was way down my back. I, uh, got a haircut and I took 15 inches off giving it to Locks of Love and then they said around your 14th or 15th day after your first chemo, that's when your hair is going to start to fall out, and it did. It would be all over my pillow. I would get a shower and I would have hair just falling off of me and it was just horrible. Um, and that was upsetting and then I

remember one night, I'd say around St. Patrick's day, in March, my last haircut was in February, yeah, so it would have been two weeks later, I said to my husband, we're just gonna have to shave it all off, I can't handle this anymore. You know, I would be at work, cause I worked through the whole thing, and I would like, I'd sit like this a lot (leaning her head over the desk) and I would like (laughing) have hair all over my desk. It was just exhausting, and so, we shaved it cause it was falling out anyway. Um, I felt better once it came out, but that was something that I thought I was ready for and then when it finally happened, I was really upset about it. (1a,d)

Scarring, disfigurement, and tattoos from radiation were concerns expressed by these women. Many of the women in this study described being left with visible signs of scarring from the surgeries and tattoos from the radiation treatment that made them feel ugly. Radiation treatment consists of body marking used for treatment planning. Some of the women expressed feelings of anger and disappointment following their treatment:

Susan: Yes. Well, that I have scars. First of all, I have tattoos from the radiation and they messed up the first set so I have double tattoos. The first set was single dots, the second set is double dots. And that bothered me because I knew they'd be permanent and when I wear a low-cut shirt they tend to show and until a few years after the surgery it upset me if the dots showed. And, I also have scars from where the surgery had been done for the port and where it had been done to remove the port. And those bother me again, when a blouse is low cut a little bit, those scars show and I feel self conscious. But I'm not going to let it stop me from wearing a top or a dress that I like (pause), I think people should know ahead of time that there could be some scarring from other things, other than the breast surgery and, for instance, that they will be getting permanent tattoos. Most women only have one tiny dot that would show in anything. I was lucky enough to have a second set so mine show more. And so, yeah, I was angry because I thought, you know, you people, it didn't affect your bodies but you are making noticeable marks on my body and ones that will make me feel ugly rather than pretty. (1b,d)

Mary: And, I really do have an issue with the doctor because the doctor was late for the procedure and when I questioned him why, why are my breasts like this, they shouldn't be flat, the nipples look like there's a silver dollar and it's flat and the profile is flat. There's a flat breast, and.... there's a large breast and a small breast. And, I asked him if it could be corrected and he said, no, it can't be corrected. But he was late for the procedure and he marked my body while I was lying down and that's why there's a difference.....And, if he would just say that. (1b,d)

Jan: Um, there were periods where you feel ugly and you don't have your wig on and you look at all the scars because it is major surgery and you know, especially the

stomach surgery is from hip to hip. Um, the reconstruction, of course there is scars there, kind of in the shape of an anchor. And then on the other side where I had the reconstruction it really isn't bad, it's just kind of one straight line from the middle of my chest going over to underneath my arm and then, of course, where the lymph nodes, there's another 2½-inch scar. So, you feel kind of ugly, you know, when you look in the mirror, but thank God I have a wonderful husband and he never made me feel any less. (1b,d)

Although most of the women reported that they knew chemotherapy would cause them to lose their hair, they reported being unprepared for some of the other appearance-related aspects of their breast cancer treatment. Some unexpected appearance-related issues are detailed below:

Tammy: Okay. You know short term, of course, I've had, you know, all the hair loss. Um, I lost my eyebrows, my eyelashes, everything, except for some reason, the hair on my knees continued to grow (laughing). Horrifically, actually, which is a little strange, I looked like I had bags on my knees. You know, it was very funny. And, I have two, probably 8-inch scars across my back from the reconstruction where they took my dorsal muscles and used those. Um, I have no feeling really in my new breasts. Um, and it was kinda weird cause, you know, I still don't have my nipples which is odd. Um, what else, my hair's growing back. It's completely a different color. It's black and white, actually, which is kind of odd because I normally have brown hair. Oh, I forgot this, I had profound acne from the steroids. (1a,b,d)

Jan: Um, prepared for it? It's a shock. It's a shock the day that, it was 11 days After I started my chemotherapy that I started brushing my hair and it, my hairbrush was just loaded with hair and it just fell out like in globs. And by the next day, I had none. So, you're never quite prepared for what you'll look like. Um, the scars were quite hideous to look at, especially the stomach. (1a,b,d)

One of the participants described feeling surprised when she lost her eyelashes and today, six years later, "They never returned". Another participant discussed the effects of losing her nose hair:

Kathy: Oh, yeah. You definitely feel insecure when you don't have hair (laughing). (1a)

Kathy: I mean through the whole thing I wasn't feeling that confident at all. Um, I think the make-up helped. Um, and I think, I'm really good at strong appearances, especially when I was at work. I tried not to let people see if I wasn't feeling good or something like that. I think I certainly had to try harder (1a,c, 2a).

When asked if she thought it was important to address appearance-related issues:

Kathy: I think yeah, definitely. Um, because your whole body is changing. I mean everything is changing. Um, I mean the hair thing is one thing, and I joke about the hair. You know, the hair on your head is one thing, but more upsetting was the hair in my nose, when that all fell out, when your nose runs, your hair kinda, I mean, I couldn't stop my nose from running. I mean I missed my nose hair more than I did anywhere else. (1a,d)

Another woman described her experience with lymphedema, which resulted in having to wear “what they call a sleeve in a glove to contain the swelling”. She stated that this condition prevented her from returning to work and has resulted in going on disability, something that she was definitely not prepared for. She described that she continues to be very self-conscious of wearing the glove. According to Anllo (2000), “While still in the midst of the initial shock of diagnosis, they must submit to disfiguring breast surgery, which sometimes results in a permanent swelling of the arm” (p. 244). As breast cancer treatments altered the women's appearance, the newly altered appearance contributed to modifying the women's perception of themselves.

Many of the women identified feelings of depression resulting from their appearance-related issues of breast cancer treatment. The diagnosis and treatment of breast cancer can be a stressful life event affecting many aspects of a woman's life (Bertero & Wilmoth, 2007). According to Anllo (2000), many women don't realize the full impact of their illness until finishing all of their treatment.

Most of the women described feelings of fear and anxiety when initially diagnosed with breast cancer and shock and depression when they actually lost their hair.

Lily: Well, losing my hair was very, it makes you depressed. Um, so, I'm stage 4. When I knew I was going to lose my hair, I started to get depressed. (1a,d)

Tara: The second time I was diagnosed I was scared to death and it probably took its toll. I didn't want to eat anything. I just wanted to shut myself away. (1d)

Tara continued in psychotherapy treatment stating that she doesn't go as often as she used to but feels as if it has helped her get through some very tough times.

4.2. Changes in Social Functioning and Social Network

Many of the women described that although they had appearance-related changes they reluctantly left the house to assume their daily roles of partner, employee, volunteer, and mother. Many of the women complained of feeling self-conscious even with the wigs on. They also described the wigs as being hot, itchy and, along with the bandanas, scarves, and baseball caps, "quite revealing of the disease". The sub-themes, disruptions related to physical functioning, placing less value on themselves, importance of support networks, and crossed boundaries are also woven throughout the following descriptions.

One of the women stated:

I did have a wig that I wore once. I didn't like it, itchy. My husband didn't like it on me so I decided not to wear the wig and to wear bandanas and baseball caps. But the first 2-3 weeks after I lost my hair I was very hesitant to go outside. Um, I was very conscious that my children would be uncomfortable being with me. They're both in school. I still wanted to be very involved in volunteering at their school, going to baseball games, and I remember the first baseball game I went to with a bandana, people looked at me and I was very conscious. They knew what was going on, but people don't mean to stare but they do. The people were very supportive. They would give me a big hug, but I was still very, um, I don't say I was embarrassed, I was just, I didn't know if people were going to ask me what was going on. I just really didn't want to go into it. I didn't really want to have to talk about it. But, obviously, people knew because I didn't look like me. Um, definitely self-esteem. (1a, 2a)

At the time of diagnosis all of the women were employed either full or part-time.

They described many physical feelings of fatigue and nausea as well as appearance-related concerns that resulted from their cancer treatment. Some women described missing work to attend treatments and doctor appointments. They began to redefine and

place less value on themselves. Again, self esteem takes a nose dive. Their situations are detailed below:

Jan: Um, I quit once my surgery, or my chemotherapy started because I had so many doctors' appointments, um, in the one year I had over 60 doctors' appointments between the chemo, tests and blood work. Um, it was every day I was having to miss work, and so, at least part of the day. And I found it very difficult, cause I only worked part-time. And, so, um, I just gave it up at the time. (2a)

Tara: Um, as I said, in the beginning when I had my first round of chemo, I felt fine, so I continued to work but my boss allowed me to work from home because my white blood count was low and she didn't want me to get sick. Um, you know I work in an office, they're always sneezing and coughing, and she said, let's, you work from home while you're having your chemo, um, and then you can come into the office afterwards. So, the first month I did work from home. The second month I just called HR and said I can't do this anymore and they were very understanding. They understood. They said, "I didn't know how you did it for a month, we'll support you whatever". So, my oncologist just wrote her, a letter, to them, basically saying, you know, that I was going to be out for four months and there was no question about it. (2a, 2b)

Jane described her work situation at the time of diagnosis and treatment:

Jane: Well, I was working as a school nurse and I cut my hours back a lot and I kept just one school. And the reason I kept this one school was because where the office was, um, it was in the back of the building, um, there weren't many kids that would come down to see me and I was really able to work and kind of still be isolated. So, I don't think my co-workers, I hadn't been there that long so I don't think they, they had no investment in me. I didn't know anybody that well. Um, I wasn't there every day. Um, I wasn't like an intricate part of their lives, so I don't know that they thought about it either way. (2a)

Women in the study described a decrease in sexual functioning due to a number of insecurities related to their body changes as a result of their breast cancer treatment.

Low sexual desire and low sexual satisfaction was attributed to the drug Tamoxifen which was reported to cause sudden onset of menopausal symptoms. Some of the women described hot flashes, vaginal dryness, and fatigue as side effects of the drug.

Some of the women were more concerned with the outward appearance-related changes such as weight gain, scarring, and disfigurement. Women described numbness

and total lack of sensation in both their normal and reconstructed breasts. Poor body image and negative self-talk attributed to a lowered self-esteem and lack of sexual desire described by the women following diagnosis and treatment.

One woman described being preoccupied with negative self talk while engaging in sexual relations with her partner. This participant described her fears:

Jane: Um, well, I wasn't very confident. I wasn't. It's very difficult to have sex and keep the wig on and, so, I would kind of, you know, avoid that. And then, yet, when I would avoid it and I would kind of be reluctant to, I would never initiate it. Um, and then I would find that if he wasn't initiating it, it was because I was hideous and, um, you know, of course he wouldn't want to have sex with me because I'm bald and I'm, you know, I look like a cancer victim and so he couldn't really win either way. I didn't really want to have sex because I didn't feel good about anything and if he wanted to, you know, I really didn't want to have it and then if he didn't initiate it, it was why aren't you initiating it, you know, I guess your lying, you don't look that good...and so, that guy could not win, in that instance. Um, and he was pretty understanding through it all. (1a, 2a, 2b)

When asked if the breast scarring bothers her:

Jane: Yes, Yes, it does. And, it does so, I mean, there's two specific times that it really affects me, um, one is during sex (1b, 2a).

Jane's description related to her sexual experience with her husband was riddled with self-disparaging statements.

One participant described having her ovaries and fallopian tubes removed because she was considered a high risk. She reported going through menopause at age 40. "I wasn't interested in sex at all". Another participant reported, "I don't think we had sex at all. So, from June of 2002 until January of 2003 I don't believe we had sex at all". (2a)

Feeling accepted and supported by family members, friends and co-workers helped many of these women to accept the appearance-related issues of their treatment.

This led to an acceptance of self and an improved self-esteem. One woman stated that her husband would go to all of her support meetings with her:

My husband is very understanding about, um, that sort of thing. You know, I've been to support groups where husbands, where women have told me that when I would go to support group meetings my husband would always come with me. But a lot of women, their husbands wouldn't come because they were either embarrassed to talk about breast cancer and mastectomies or they just weren't interested in their wives anymore and that was sad. But my husband would always come with me and be there. (2b)

Many women described aspects of support:

Jan: Oh, he just, he was just wonderful. He said it didn't matter at all and he loved me just the way I was.....And at one point I had gotten a turban and I came home with it and I showed it to him, and he said, well, I said I got two of them and he said for what? And I said, one for you. He said, well, I'll wear one. So we sat at the dinner table that night with our turbans on and just got hysterical laughing (laughing). (2b)

Jane: I never had any bits of conversation with anyone except my kids about my hair. And my son would also wear one of those nightcaps to bed the whole time that I was bald. He wore this little cap to bed just like I did so I wouldn't feel bad, just precious. Yeah. (2b)

Tara: Um, my daughter was five. She would wear my bandanas with me and my scarves. I mean, I made her part of my make-up routine, my scarves, my hats. (2b)

Betty: Um, my children were in their teens, um, my older son, who's a bit dramatic offered to be a bone marrow donor if I needed it (laughing). (2b)

Mary: My partner actually was my advocate and she embraced me 24/7. (2b)

Karen: Oh, everybody was wonderful. You know I worked through the whole thing. Um, I think I had my mastectomy for about six weeks. They were very positive. I'll just say one story here, was that a bunch of us went out to lunch and were coming back to work and it was really windy that day. The wig just kind of blew off my head. And it just got ripped by it and then everybody started to laugh and it was really one of those things that you remember. Everybody was positive. They told me what a great job I was doing and everything. (2b)

Some women described experiences where they were approached by strangers in public places. They described the appearance-related changes as “wearing a veneer of vulnerability” which opens the door for strangers to approach them. Although some

women responded well to the support, others describe feeling angry, insecure, and violated. When asked if she ever felt the need to hide appearance-related side effects:

Tammy: No, the only reason I may have worn a wig or something like that was that people felt the need, strangers felt the need to come up to me and ask me random odd questions that were really none of their business. And, I think if I blended in more with society perhaps they wouldn't have done that. (2c)

Some of the women responded well to the crossing of boundaries by others. For instance:

Susan: Um, I took my wig off one day because I had a horrid headache and I was at the hospital with my mother who had broken her hip and the nurse's aide said to me, "I don't know you. I don't have any right to say this but you look much cuter without your wig". I never put that thing back on my head. It was the happiest day because I could go without it and just be me. (2c)

Kathy: I can't tell you how many people came up to me during the whole thing, women, never any men, but always women, would, you know. I would always have a hat on or something and it would usually be "Are you in treatment?" or "Do you have cancer?" or, you know and I would say "yes", you know, I am....I'm not going to lie to anyone. And then they would tell me about how they had breast cancer or ovarian cancer and, you know, so many people would give me their cards and, you know, it was just fine. I was in the airport one time and I was going to California and this woman came up to me and gave me a huge hug and she said, "Oh, I know what you're going through, this is going to be better, you're going to get through this", and she's like, you know, "good for you that you're traveling, you're doing things", and I'm like, yeah! (2b,c)

Both Susan and Kathy described holding assumptions about their appearance, which caused them to feel insecure and self-conscious until they received support from strangers. These validating interpersonal connections were described as important to the women's sense of self, enhanced their personal adjustment, and improved their self-esteem. The sub-theme of importance of a support network (2b) is apparent in these two interviews. The women reported an improvement in self-esteem and social functioning when feeling accepted by others. Further, this acceptance by others, ultimately, resulted in self-acceptance.

Tara detailed a situation that arose in the supermarket check-out line when a customer was staring at her. She stated that the women made her feel very uncomfortable. “She then demanded that I take off my baseball hat”. Tara reported that the woman caught her off guard. “I didn’t know what to do so I actually took my hat off, right then, right there. The woman then said you are much more beautiful without it and gave me a hug.” Tara stated that she felt empowered and never wore the baseball cap again. (2b,c)

4.3. Self-Advocacy and Empowerment

Many of the study participants agreed that it was important to be advocates for themselves. They reported that it was essential to ask questions, get second opinions, and research treatment options. One woman described a situation where she felt rushed by her doctor. Another woman stated that her plastic surgeon left the hospital in the middle of her treatment and she had to find a new doctor. Sub-themes of finding a voice, light at the end of the tunnel, and gained sense of control are apparent in these descriptions.

Some of the stories are detailed below:

So, I went to the surgeon, she told me she had to do some blood work and stuff, but she told me she had to do what’s called an excision biopsy which means surgically going in and taking a piece of the cyst and having it diagnosed and then to have to know what you have to take. And I met with her shortly before I went into the operating room and I said specifically to her, please, whatever you have to do, do it. If you need to do a mastectomy, please do not wake me up to tell me you have to go back, put me under again and take my breast off. I said whatever you have to do, I would like you to do it. (3a)

Two of the study participants were in the health care field and had conducted their own extensive research prior to having their breast cancer surgeries. Jane reported that having this knowledge made her feel empowered in some situations yet brushed off in others.

Jane: And then I went to a breast surgeon and because of having two tumors in the same breast, they recommended a mastectomy and I requested having a double mastectomy. They kind of brushed that off, said they really didn't feel that was necessary. I decided to have reconstructive surgery at the same time as my surgery. If you were to have one implant and one not, you would have one that's much higher and more firm. So they told me this was the way to go. And the breast and the plastic surgeon too also said, you know you don't need to have both done. So, again I was told, you know, not to worry about that. So, I had that done and ended up having, I lost count, about five more surgeries after that which was all cosmetic. Um, trying to get the other breast to look, you know, similar to the other breast. Having nipples reconstructed, having nipples reduced, having tattoos, having a breast lift and an implant put in my unaffected breast. And all of this was cosmetic. (1b,d, 3a,c).

Jane: Um, so yes, it helped me to be a nurse, that, you really, every person needs to be their own advocate and because there were things that I suggested that they agreed to and had I not suggested them, they would not have offered them. And, um, for instance, they wanted to put a port in for the chemo. Well, that's a surgery. You know, you have this little pick line put in where it's a permanent IV basically, it's usually up by your clavicle, and um, it leaves a scar and I thought. I said to them, I said, I don't want it. I'm only getting four IVs, I didn't need six months of chemo. Certainly that type of procedure would be necessary because you know, six months of trying to find a vein every time, it would be difficult, but four times, you can have an IV four times. It's not that it hurts me. And they said, okay. And that's why I didn't get a port. (3a,c)

Jan: I started noticing atrophy in the one breast. It was the same breast I had cancer in previously. Um, I was just becoming very, very small and I brought it to the attention of the radiologist and he just said it was because of having had radiation, that there would be changes and kind of dismissed it. And the oncologist did as well. When I went for the mammogram it did show something. So they sent me for an open MRI and this was when they were quite new. In fact, I was one of the first patients to ever have the test on the scoping MRI which was back in 1999. And, believe it or not, it came back negative which I kind of think it may have been a misreading there that I don't know. But the change continued. I just kept getting smaller and finally I decided to go to my surgeon and the minute he looked at me he said, Um, and he could feel something, there was also something that you could actually feel. And he thought it was suspicious. He did a biopsy and told me that he thought it was a very large tumor and again I was in there very shortly after. And he had done the mastectomy, did the lymph nodes which were completely clear and, um, from there I had the reconstruction and TRAMflap and started the chemotherapy once I began to heal. (3a,c)

Mary: Appearance related changes? Well, the nipple reconstruction is awful and if you'd like to see, I can show it to you. I don't have a problem with, ... One thing that I have learned is that women that have had the TRAMflap reconstruction, we share this information and we look at each others breasts and we embrace each other because, you know, we can relate to what each other has gone through. And

thus far, I have the worst reconstruction and I have realized going through this that I really have to be my own advocate, especially when, in dealing with doctors. If you don't, no one else will. And I think we need, (short pause) in dealing with doctors, you have to be diplomatic and I just have to diplomatically approach the surgeon. And I struggle with that because he and one breast, just don't work and the right breast there's no nipple and it's just so mismatched and it's a mess. (1b,d, 2b, 3a)

Mary: Sense of self (pauses) I think when it comes to getting dressed or going to a special occasion or something and I look in the mirror. Because I think all women embrace their girls and I really embraced mine and I enjoyed them, you know, they were a nice enhancement with a female body. So now I just, I don't like it. I don't, it's not so much that I don't feel attractive. I didn't get what I expected. (1b,d, 3a)

Mary elaborated that she didn't get what she expected related to her surgery. She described disappointment in her surgeon and the outcome of the surgery. She wanted to be validated, to express her feelings of disappointment and frustration. Many of the women reported following up with cosmetic procedures to "fix" their altered bodies.

Mary later described how her mother was upset with her because she chose to have a double mastectomy. Mary emphasized the need to educate people like her mother, who she described as "totally illiterate" when it comes to breast cancer. She stated that women are not informed as described below:

Mary: And when I tried to explain to her the TRAMflap, you know, and she was like, "Why would you want to do that to your body? Why don't you just do a lumpectomy?" and I explained to her the size of the lump and blah, blah, blah, and she still didn't get it so I just went to the American Cancer Society website and just printed information so she would understand the different stages, the difference between a lumpectomy and a mastectomy and a double mastectomy.

Unfortunately, not all women have resources at their fingertips. According to these women, the need for education is imperative once you've been diagnosed with breast cancer.

Throughout the interviews most women found it extremely important to emphasize to other women who are diagnosed with breast cancer that some of the

appearance-related changes, particularly hair loss, are only temporary. They all wanted to give other women the reassurance that if they experience the appearance-related changes resulting from breast cancer treatment that they would look “normal” again.

Tammy: Just that it’s very short-lived. At the time it seems like a travesty, but it’s very short lived. So, I mean, the hardest part is, you know, some women end up gaining some weight, which I think is very hard on your mental stability, depending on who you are. And, um, the weight comes off, the acne goes away, your eyebrows grow back in, you know, pretty much overnight. Um, it’s all very short-lived. (3b,c)

Susan: You will not constantly feel ugly because you will grow your hair back. (3b,c)

Tara: Um, I would just let them know that, you know, you are not alone. That there are lots of women out there that would want to help them, but it’s temporary, it’s when you lose your hair, it will grow back. When you feel really crappy, you’re not going to feel that way forever. Um, radiation will affect your skin, but it won’t affect it forever. You can get through this with support and family support and you just, you know, just be strong because there is a light at the end of the tunnel. (2b, 3b,c)

Lily: Um, I guess the most helpful thing is to, you know, once they realize that it’s a possibility, cause I ran into people who did not lose their hair, um, to just know it’s a temporary thing and there’s all kinds of things out there. Wigs and make-up and had to have all kinds of things to make you look better, or about your hair. And, It’s only temporary. Your hair’s coming back. Just like a part-time thing is going to happen and then as soon as the chemo is over, your hair is going to start growing back. It’s just a temporary thing that you have to go through. Cause, it’s not forever. I think once we realize this is not forever, this is just a temporary thing that we have to go through.....then, we’re okay. (3b,c)

Betty: Um, as my very first breast cancer buddy told me, she had her breast cancer 21/2 years before. She said, “Your hair really will grow back”. Um, it was encouraging for her to look normal to me, you know. She made it through and she’s back to normal. You know, I think women talking to other women who’ve been through it is very important. (2b, 3b)

Jane: Um, I think talking to other people that have gone through it. You know, I was told that my hair would, you know, probably grow back very quickly. It didn’t. Um, I was worried that it was never going to come back. I was going to the doctor and saying, it’s been six months since my last chemo and I don’t have anything. I mean nothing, I was panicked. I knew other people who were getting stubble in between their treatments. So their hair was going to come back quick. Um, and I also didn’t have, you know, a short haircut to begin with. So, you know, just awful. So, um, you know, talking to people, I would tell them that, you know, not to worry if this doesn’t come back quick, it will come back and you know with me this is what happened. Just having somebody who personally

went through it and who also cares about their appearance. You know, often I would talk to people that were just like, “Oh I didn’t even care about my hair, all I wanted to do was live”. Well, I wanted to live too, but you know, I mean, yes, of course, that should be your priority otherwise you wouldn’t be doing it in the first place. But to say that or just kind of brush it off like that’s not important, it’s ridiculous. And maybe for some people it’s not. I would say to the vast majority of people, it is. So, I would think it would be helpful to talk to other women who had gone through it and could tell them how they felt and that it’s completely normal to feel ugly and unattractive but that it will change, it’ll come back. (1a,d, 2b, 3b,c)

Eventually, taking control of decisions related to personal appearance became empowering for some of the women. The women began describing an improvement in self-esteem and regained sense of self. Many of the women described making changes through diet and regular exercise programs. A few of the women stated that they stopped drinking alcohol. Others described feeling better about their appearance as a result surgical decisions, for instance, one woman reported:

Well, um, I did not have reconstructive surgery at the time. And, I don’t know, seven or eight years later, I got tired of being two different sizes and so that’s when I had breast deconstruction surgery. I had the other breast made smaller and the surgery removed some of the scar tissue from the original surgery that’s right next to the chest wall. And so, that made me feel better. Nobody really noticed it but I did, every time I looked in the mirror. (3c)

Tara was diagnosed and treated for breast cancer five years ago. She had genetic testing done and found out that she was BRCA2, a genetic predisposition to breast cancer. She had a double mastectomy with immediate reconstruction at the time. “I had two implants put in”. Two years later she was giving herself a breast self exam and felt a lump. Following a biopsy she discovered that the cancer had returned. She began chemotherapy in May of 2009, which she described as “horrible”. The chemo was followed with radiation therapy and now she is on Tamoxifen for five years. Tara states that she is now able to think about cosmetic reconstruction:

Tara: Um, I'm actually going to have a bit of more reconstruction done on my breast implants because my very first experience was not a good one. (1d, 3c)

Women described having botox, liposuction, breast reconstruction, upper lip waxing as appearance investment procedures following their recovery from breast cancer. Some of the women described wearing more cosmetics, even if it was just lipstick.

When asked about the importance placed on appearance investment prior to diagnosis, for example, did they have their hair done regularly, did they wear cosmetics, did they get their eyebrows waxed, or use any skincare products, most women felt that it was important to invest in their appearance, for example:

Kathy: I've always had really good skin. Um, I've always cleaned my skin, like, you know, in the shower like with soap, not with soap, but like with facial moisturizer or that kind of thing. I've never been big into make-up at all. Was never really, you know, really cared. You can't tell my hair is curly now, but my hair has always been curly. Um, so I never really did that much with my hair because my hair will just be curly anyway. Um, I definitely think when I started doing this whole cancer thing that, um, I definitely wear more make-up now and I really tried to make myself look more female. Cause, just being bald, you just don't feel like, you still have boobs, but I mean, you know you don't look, you look more like a guy, I think, when you're bald. (1a, 2a, 3c)

4.4. Support for A Cosmetic and Grooming Behavior Clinic As An Aspect of Breast Cancer Treatment

My last question was to ask the women about a clinic to address some of the appearance-related issues of breast cancer treatment. Although some of the women did not wear make-up or use skin care or hair care products prior to being diagnosed with breast cancer, they all felt that being prepared for the appearance-related side effects by attending a clinic was important. Some of the women described feeling less self-conscious and more supported in one of the clinics that they attended because "we were all in the same boat". Some comments are described below:

Mary: I think it's important.... I think it's important. And I went to the Look Good...Feel Better group and that's a nice program for women who are going through chemo and the radiation. Because you really do, I think, for your self-esteem, you want to pull yourself together and try to keep yourself up and build yourself up because it does. When you look good, you feel better. That's my opinion. And you feel better about yourself. So, to get up and put a little lipstick on, you don't have to do the whole nine yards, but just something. Even if it's a little perfume, you know. (2b, 3c)

Tara: There was a program. That Look Food...Feel Better program through***** hospital and when I lost my hair, um, my daughter recommended for me. It was an evening at *****where they have make-up artists that come in and they actually give you very generous, um, and it did me the world of good. They give you a large bag of cosmetics and they show you, basically, how to draw in your eyebrows, how to make....My face was dry when I had chemotherapy and they would show you the right moisturizers to use, um, how to wear the bandanas and different hats, just to make you feel, to look good and feel good and there were about twelve women that attended that night. I was a little apprehensive about going. Wasn't quite sure if I wanted to go and take my scarf off in front of strangers and have them look at me with no make-up on and then putting make-up on, but I ended up, actually, um, I was the model for the make-up artist so I sat in front of the class and she actually made me up and showed the other women what to do. It made me feel good because I went home and, you know, my husband thought it was great and, uh, my daughter, who was five, said, "oh, mom, you look pretty" and I'm glad I went there. It was a good program and I definitely recommend anyone going through it to attend that kind of seminar. You were able to keep the cosmetics that they gave you, eyebrow pencil, blush, so, a great program. (2b, 3c)

Betty: I think the one I went to was just one day, but it was very good. The clinic was very encouraging for me. There were so many women there and there were three or four, or five instructors and they all had something to teach us from different aspects about your hair or your color of your clothing, your make-up, or something. It was encouraging to see so many other women in the same place. (2b, 3c)

Betty went on to say that she had never heard of the program before she had learned about it through her oncologist's office. She thought the program would be helpful for women diagnosed with breast cancer, "Publicity for the program is essential."

This chapter summarizes for the reader verbatim quotes by the participant's, themselves, to deliver their messages related to altered appearance related to their breast cancer treatment and how it affected their sense of self, self-esteem, and social

functioning. The three major themes and sub-themes that surfaced during data analysis were also reviewed in this chapter.

CHAPTER 5

Discussion

The present study was to explore whether appearance-related issues of breast cancer treatment affect sense of self, self-esteem, and social functioning. In this study female breast cancer survivors described their experiences related to their altered appearance. The results unearthed in this study were consistent with issues presented in the literature related to altered appearance and how it affects one's thoughts, feelings, and behaviors. This chapter will connect theories in Chapter 3 to the findings in this study.

This study confirmed that women have specific concerns adjusting to the disease and its treatment as they are associated with altered appearance. These aesthetic changes have been reported to disrupt many aspects of a woman's sense of self, which include but are not limited to, self-image, self-esteem, self-concept, self-confidence, and body-image. Disturbances in body image have been linked to low self-esteem (Striegel-Moore & Franko, 2002). This adjusted sense of self related to breast cancer treatment has been described as having an impact on the women's self-esteem which resulted in disturbances in several aspects of social functioning such as employment, sexual intimacy, and social events.

Research shows that scarring and disfigurement to a woman's body can result in changes to self-perception and lower ratings of attractiveness (Ogden & Lindridge, 2008). Today an increasing number of women are undergoing surgery for breast cancer which may include lumpectomy, mastectomy, breast reconstruction, and placement of a port, all of which have been described as concerns for the women in this study. Fobair et

al. (2006) found that these concerns are common following surgical and adjuvant treatment.

A major contribution of this study was that it validated existing knowledge on the topic of altered appearance in women with breast cancer. This first theme, changes in self concept due to changes in appearance, is consistent with the findings of Bertero and Wilmoth (2007) in their fourth interpretation, described as redefinition of self. They defined “body picturing”, as a result of breast cancer treatment, causing the women to feel “not normal” or “altered” to a point where they did not recognize themselves. The study women didn’t look the way they wanted to look and needed support around that.

According to Sullivan (1953, p. 350), interpersonal theory describes “the person’s personification of himself is not very estimable by comparison with his personifications of significant other people. For example, Tara was concerned that other people were looking at her in a different way, Betty described needing to be supported by other people, and Jane’s detailed description in the supermarket are all indications of interpersonal interactions and how they affected the women’s sense of self which, in this study, was interconnected with the women’s self-esteem.

As described above, altered appearance can cause the women to have false messages or assumptions about themselves. Tara described: “I felt lots of people who knew what was happening were looking at me in a different way.” Jane stated that maybe she wasn’t as unattractive to other people as she thought she was. Consistent with the interpretation of attachment validation related to womanhood/femaleness in the study by Bertero and Wilmoth (2007), the women in this study described questioning whether

they were still desirable women. The sub-themes were interwoven and interconnected throughout the main themes of the study.

Sarwer (2006) reported that a person's appearance can shape their self-image; ultimately, affecting the way they deal with others. According to Beck (1979), cognitive theory maintains that how an individual structures his or her life experiences largely determines how he or she feels and behaves. Oftentimes appearance-related side effects of breast cancer treatment can result in holding assumptions about oneself. In this study the women described how thoughts about their altered appearance directly interfered with their functioning.

These findings are consistent with Interpersonal theory which postulates that people with low self-esteem minimize their anxiety through some degree of social isolation, that is, to some degree they limit their contact with others (Sullivan, 1953). Sullivan described one's deep, absorbing preoccupations, "in which one loses all touch with things outside of oneself short of fire, there is great centering of conscious referential process on tiny little signs, often grossly and dreadfully misinterpreted, in the somatic organization of the body" (p. 356). Sullivan pointed out that interpersonal interactions and environmental influences serve to modify perception of self as well as one's external experiences with others. Interpersonal theory places emphasis on the formulation of a set of internal assumptions, ideas, and fantasies about other people and oneself, referred to as personifications. Appearance, therefore, is not just personal but societal.

According to cognitive theory these assumptions can lead to distortions, catastrophizing, exaggeration, shame, and negative self-statements. These distorted

patterns of thinking often lead to misperceptions about oneself, one's environment, and one's experiences. The perception of oneself becomes inadequate along with a negative view of the world. This study provides evidence that changes in appearance related to breast cancer treatment caused these women to make assumptions about themselves. The women reported holding assumptions that they would be judged by their families, co-workers, or strangers in society. Some women reported assuming they were unattractive or less feminine because of their breast cancer diagnosis and treatment. These women feared being ostracized or marginalized in their community. They described these assumptions as having an impact on their role as partner, co-worker, and person in their environment.

It is important to note that in the third theme, related to advocacy and empowerment, when the women received positive support by family, co-workers, and strangers it seemed to result in a more positive self-concept. If one receives acceptance and support by others then those feelings are mirrored back from the individual. The women described feeling more comfortable around those people they knew and trusted. The women also described feeling uncomfortable around strangers, people they didn't know, until that stranger provided positive support. The women apprehensively left the safety of their homes describing feelings of vulnerability and self-consciousness. The women held "false beliefs" that they would be judged by others. Therefore, in addition to the use of cosmetics, hair and wig care, etc., a cognitive behavioral intervention should be explored to evaluate efficacy with breast cancer survivors and the assumptions they develop related to these appearance-related changes.

Interestingly, as described by Cozolino (2002) in Chapter 3, the brain exists in relationship with other brains and when acceptance is demonstrated by others it can produce acceptance of oneself; ultimately, healing suffering. This was confirmed by several women in the study who were encouraged to expose their bald heads. These women reported feeling empowered describing that once they removed their head coverings in public they never felt the need to cover their head again.

Crossed boundaries, one of the sub-themes of the study, caused many of these women to go on an inner journey of self discovery. Nezu & Nezu (2003) referred to this as the “true self”. Whether positive or negative the feedback gained from society, frustration related to health care, and the desire to have a sense of control resulted in self advocacy. The women began to find their voices to fight for themselves. This gained sense of control appeared to have created a domino effect. The women reported that advocating for themselves led to feelings of empowerment; ultimately, this improved their self-esteem which improved their sense of self and their overall social functioning. This renewed sense of self-esteem enabled the women to move from the victim role which placed them in the driver’s seat of their own lives.

It is also important to note that this study does not promote or suggest the use of cosmetics or a particular program. It is only reporting the interest in cosmetic care that the women, themselves, described to build support networks and camouflage the negative side effects of breast cancer treatment.

5.1. Clinical Implications

This study recognizes that coping with appearance-related issues as a result of breast cancer treatment was a major concern for these women. These findings have

numerous implications for clinical social workers. First, understanding and validating the concerns revealed in this study can assist clinical social workers in their ability to be more mindful of this important aspect of breast cancer treatment and provide the necessary interventions. According to Titeca et al. (2007), although these side-effects of breast cancer treatment may have a significantly detrimental impact on a patient's quality of life they are often not recognized as important by healthcare professionals. Perhaps this is because of the lack of knowledge in this area that this study hopes to bring to light.

Cozolino (2002) reported, "As a therapist, one of my primary goals has been to shift my clients' experience of anxiety from an unconscious trigger resulting in avoidance into a conscious cue for curiosity and exploration" (p. 33).

Second, as health care professionals clinical social workers are trained to validate feelings while meeting their clients where they are, helping to improve social functioning and develop effective coping strategies. One of the central roles of a social worker, as the psychotherapist, is to provide psycho-education. Social workers, whether in clinical hospital settings or outpatient practices, "have an important role in helping individuals and their family adjust to the diagnosis and treatment of cancer" (Bourjolly, Kerson, & Nuamah, 1999, p. 16).

Lastly, if we are going to continue to work with this population it is important to feel comfortable assessing these areas of outward appearance enabling us to address the "whole" person both inside and out. Throughout the research literature it has been noted that these appearance related issues have resulted in psychological issues for many breast cancer patients; however, very seldom do we see them being referred for psychotherapy. Therefore, this study suggests the importance of clinical social workers in hospital

settings assessing appearance-related issues of breast cancer treatment to help women in their adaptation of these issues and refer to outpatient psychotherapists as needed.

Further, to bring light to this topic can advance the knowledge of psychotherapist in developing ways in which we can prepare, educate, and implement clinical interventions to support these women as they struggle with the physical, psychological, and appearance-related aspects of breast cancer treatment. We have the responsibility to transfer what we know to our health care treatment teams, social work colleagues, as well as the next generation of healthcare providers to prevent them from disregarding this important aspect of psychotherapeutic intervention for women in treatment for breast cancer.

For example, a recent study by Hunter, Coventry, Hamed, Fentimen, and Grunfeld (2008) evaluated a cognitive behavioral therapy (CBT) group, which consisted of relaxation and paced breathing techniques, as an intervention to alleviate menopausal symptoms in women following breast cancer treatment. Although they report that further studies are needed, their research found clinically significant data to support a CBT group intervention to reduce hot flushes and night sweats in women who had undergone treatment for breast cancer.

Research indicates that psychosocial support can be helpful with the psychological stress experienced by women who are going through breast cancer treatment (Badger et al., 2007). Fobair et al. (2006) found that addressing body image and sexual functioning were essential in improving the quality of life in women with breast cancer. Annlo (2000) reported that psychotherapy can be effective in helping women cope with these difficult changes in body-image and sexual functioning; however,

stated that most mental healthcare providers are not comfortable addressing these issues. Consequently, many of the participants in this study struggled with alterations in sense of self, self-esteem, and social functioning without seeking professional support.

Denzin & Lincoln (2005) reported that, “The interviewer becomes an advocate and partner in the study, hoping to be able to advocate social policies and ameliorate the conditions of the interviewee” (p. 696). Bringing awareness to these appearance-related issues can be a first step in recognizing that they actually do exist. Many suggestions were made by the participant’s during the interviews. One such suggestion was to provide neighborhood educational clinics where women could go seven days a week to gather information, support, and counseling. Another suggestion was to educate and empower these women with both group and one-on-one cosmetic and grooming instruction to prepare women for the appearance-related changes of breast cancer treatment.

A case study by Badger, Segrin, Meek, Lopez, & Bonham (2004), identified telephonic counseling sessions as an effective intervention in improving psychological distress in women receiving treatment for breast cancer as well as their families. By developing a rapport with the client and her support network via telephonic sessions this method can meet the client where she is and assist with symptom reduction of anxiety and depression by providing education and support. According to Badger et al. (2004), “Brief, focused psychosocial interventions delivered over the telephone may be a solution to improve symptom management and quality of life for women receiving adjuvant therapy for breast cancer and their partners” (p. 1003). This type of intervention could possibly be useful for women struggling with appearance-related issues of breast cancer

treatment due to their initial reluctance to leave the safety of their homes. Through telephonic session the clinician can reach the client and their family where they are while helping to build support, and provide resources, education, and encouragement.

5.2. Strengths

First, this study provided a thick description of the women's reality, which validated existing knowledge and helped to gain new insights. Second, this study was able to reach data saturation with no new data that was forthcoming after the last interview. Third, for credibility, member checking was done to ensure that what was being transcribed and analyzed was, in fact, what was meant by the participants. Lastly, the study's findings may be transferred to other well-educated breast cancer survivors.

5.3. Limitations

The interviewed participant's for this study were representative of one group of women. The sample lacked a wide range of cultural diversity and socioeconomic backgrounds; therefore, the results cannot transfer to all women who have received treatment for breast cancer. However, this qualitative study was to interview a small heterogeneous sample as a way to secure rich description of their reality as it pertained to appearance-related issues arising from their breast cancer treatment. This study described and gave voice to the interviewee's perceptions.

5.4. Future Studies

The findings lend support for further research into the area of appearance-related issues of breast cancer treatment. These are major concerns that, to date, are not being fully addressed by the social work profession. Although this study was able to validate existing knowledge, many years later these appearance-related issues continue to remain

unassessed by many members of the healthcare team. In 2009 a self-report measure of body-image and sexual adjustment was developed and found to be a valid and reliable mean for assessing these areas in breast cancer patients (Dalton et al., 2009). This scale addresses the “potentially unique body image disturbances experienced by breast cancer patients” (p. 287). A quantitative study could move this study forward by using this scale known as the Sexual Adjustment and Body Image Scale (SABIS) to measure these disturbances that are unique to breast cancer patients. In future research this could lead to identifying more evidence based interventions specifically designed to target these very valid concerns.

More research is needed to further explore assumptions related to altered appearance in women with breast cancer and the effectiveness of a cognitive behavioral intervention. This research is essential in assisting clinical social workers in gaining a sufficient contextual understanding of the appearance-related issue when working with this population and developing effective interventions. Further research is required to understand, from a clinician’s perspective, the reluctance to assess this very important aspect of treatment. Additionally, studies could include a more diverse sample of women from different socioeconomic backgrounds.

In conclusion, despite limitations, this study suggests that women would like to be educated about the potential appearance-related issues of breast cancer treatment. Having this knowledge can empower women to consider their choices when making decisions related to their breast cancer treatment. Women diagnosed with breast cancer need to be prepared both educationally and psychologically from initial time of diagnosis to determine their treatment options. By identifying resources and having this valuable

information available at their fingertips, social workers can provide breast cancer survivors with information and education necessary to make more informed decisions. Literally, women need to stop putting their bodies into the hands of others without knowing the consequences of their choices, how those choices will affect their appearance, and how their changed appearance will affect their sense of self, self-esteem, and social functioning.

APPENDIX A

Recruitment Flyer



Volunteers Needed For a Doctoral Research Study

Are you a woman who has been diagnosed and received treatment for breast cancer? If so, please consider participating in a doctoral research study to discuss appearance related issues as a result of your breast cancer treatment. This research project will help to assess the needs of women in their recovery from breast cancer treatment. Participating is confidential and involves:

- **A confidential background Survey identifying demographic information for purposes of the study**
- **A signed consent**
- **A 60 to 90 minute interview**

**If you are interested in this participating, please contact:
Margaret Preston, LCSW, DCSW
215-805-1742 or
e-mail: hp6250@aol.com**

**This study has been approved by the University of
Pennsylvania Institutional Review Board**

APPENDIX B

Consent Form

Title of the Research Study: An Exploration of Appearance-Related Issues of Breast Cancer Treatment on Sense of Self, Self-Esteem, and Social Functioning in Women with Breast Cancer

Protocol Number:

Principal Investigator: Jerry Bourjolly, Ph.D.

3815 Walnut Street

Philadelphia, PA 19104-6179

215-898-5523 e-mail: jerri@sp2.upenn.edu

Co-investigator: Margaret M. Preston

11 Rose Lane

Flourtown, PA 19031-1909

215-805-1742 e-mail: hp6250@aol.com

Emergency Contact: Margaret M. Preston

You are being asked to take part in a research study. This is not a form of treatment or therapy. It is not supposed to detect a disease or find something wrong. Your participation is voluntary which means you can choose whether or not to participate. If you decide to participate or not to participate there will be no loss of benefits to which you are otherwise entitled. Before you make a decision you will need to know the purpose of the study, the possible risks and benefits of being in the study and what you will have to do if decide to participate. The research team is going to talk with you about the study and give you this consent document to read. You do not have to make a decision now; you can take the consent document home and share it with friends, family doctor and family.

If you do not understand what you are reading, do not sign it. Please ask the researcher to explain anything you do not understand, including any language contained in this form. If you decide to participate, you will be asked to sign this form and a copy will be given to you. Keep this form, in it you will find contact information and answers to questions about the study. You may ask to have this form read to you.

What is the purpose of the study?

The purpose of the study is to explore appearance-related issues in women who are receiving treatment for breast cancer and whether they affect sense of self, self-esteem, and social functioning. This study is being conducted for a doctoral dissertation.

Why was I asked to participate in the study?

You are being asked to join this study because:

- ✓ you are a female who is 18 years or older
- ✓ you are currently receiving or have previously received a course of treatment for breast cancer, stage 1 or higher,

- ✓ your treatment includes radiation therapy, chemotherapy, or hormonal therapy.

How long will I be in the study? How many other people will be in the study?

The study will take place over a period of six months. This means that we will ask you to be interviewed for a period of 60-90 minutes to discuss appearance-related issues of your treatment for breast cancer.

You will be one of 12 to 25 people in the study.

Where will the study take place?

You will be asked to be interviewed in a place that is most comfortable for you, whether that is in my private office located at 1407 Bethlehem Pike, Flourtown, PA, in your own home, or an agreed upon private location.

What will I be asked to do?

You will participate in a 60-90 minute interview to discuss your treatment and any appearance-related issues. The interviews will be audio-recorded. All measures will be adhered to for protecting confidentiality.

What are the risks?

There are no known risks of participating in this study. A potential risk may involve the psychological discomfort of discussing the diagnosis of breast cancer and the appearance related issues as a result of treatment. Should you feel ongoing discomfort at any time, you may elect to stop the interview for a few moments, or you can decide to stop participating entirely. In the event that the emotional distress should continue, this researcher will assist you in finding a therapist.

How will I benefit from the study?

There is no benefit to you. However, your participation could help us understand whether a cosmetic and grooming behavior clinic could be an important aspect of treatment to deal with the appearance-related side effects of cancer treatment, which can benefit you indirectly. In the future, this may help other people to better understand ways to deal with these issues

What other choices do I have?

Your alternative to being in the study is to not be in the study.

What happens if I do not choose to join the research study?

You may choose to join the study or you may choose not to join the study. Your participation is voluntary.

There is no penalty if you choose not to join the research study. You will lose no benefits or advantages that are now coming to you, or would come to you in the future. Your therapist, social worker, nurse, doctor or will not be upset with your decision.

If you are currently receiving services and you choose not to volunteer in the research study, your services will continue.

There are no negative consequences should you choose not to participate in the study.

When is the study over? Can I leave the study before it ends?

The study is expected to end after all participants have completed all visits and all the information has been collected. The study may be stopped without your consent for the following reasons:

- The PI feels it is best for your safety and/or health-you will be informed of the reasons why.
- You have not followed the study instructions
- The PI, the sponsor or the Office of Regulatory Affairs at the University of Pennsylvania can stop the study anytime

You have the right to drop out of the research study at anytime during your participation. There is no penalty or loss of benefits to which you are otherwise entitled if you decide to do so. Withdrawal will not interfere with your future care.

If you no longer want to be in the study, you may simply drop out with no questions asked.

How will confidentiality be maintained and my privacy be protected?

The research team will make every effort to keep all the information you tell us during the study strictly confidential, as required by law. The Institutional Review Board (IRB) at the University of Pennsylvania is responsible for protecting the rights and welfare of research volunteers like you. The IRB has access to study information. Any documents you sign, where you can be identified by name will be kept in a locked file cabinet in my private locked office, located at 1407 Bethlehem Pike in Flourtown, PA. These documents will be kept confidential. The co-investigator will manage all data. All data will be stored and analyzed at the co-investigator's private office. Paper documents will be kept in a locked file cabinet in that locked office. Computer files will be stored on a password secure computer. Coded numbers will be used for all participants. All possible identifiers of participants will be kept in a locked closet in the locked office and separate from codes. Street addresses and phone numbers will be collected to confirm interview appointment and send reimbursement money for transportation, which may include gas or public transportation. Following the interview, this information will be destroyed. Audio recordings will be destroyed following transcription. Once the study is complete, the transcriptions will also be destroyed. There will be no future use of any of these recordings/transcriptions. All the documents will be destroyed when the study is over.

What happens if I am injured from being in the study?

This study poses minimal risk and there are no foreseen injuries associated with it.

If you are injured and/or feel upset and emotional discomfort while participating in the study you may contact the PI or the emergency contact name on the first page of this form. Also, you may contact your own doctor, counselor or seek treatment outside of the University of Pennsylvania. Bring this document, and tell your doctor/counselor or his/her staff that you are in a research study being conducted at the University of Pennsylvania. Ask them to call the numbers on the first page of this form for information.

If you are injured and/or feel emotional discomfort from being in the study, the appropriate care will be provided without cost to you, but financial compensation is not otherwise available from the University of Pennsylvania. If you are injured and/or feel emotional discomfort while in the study but it is not related to the study, you and your insurance company will be responsible for the costs of that care.

Will I have to pay for anything?

There are no costs to you for participating in the study.

Will I be compensated for participating in the study?

You will receive a \$10.00 gift certificate to Borders bookstore. You will also be reimbursed for transportation expenses such as gas or public transportation and/or tolls.

Who can I call with questions, complaints or if I'm concerned about my rights as a research subject?

If you have questions, concerns or complaints regarding your participation in this research study or if you have any questions about your rights as a research subject, you should speak with the Principal Investigator listed on page one of this form. If a member of the research team cannot be reached or you want to talk to someone other than those working on the study, you may contact the Office of Regulatory Affairs with any question, concerns or complaints at the University of Pennsylvania by calling (215) 898-2614.

When you sign this document, you are agreeing to take part in this research study. If you have any questions or there is something you do not understand, please ask. You will receive a copy of this consent document.

Signature of Subject _____

Print Name of Subject

Date

APPENDIX C

Demographic Data

Code _____

Confidential Background Survey

I will begin by asking you a few questions about yourself. Remember that answering these questions is voluntary and this information will be kept confidential. You may skip any questions that you do not want to answer. There are no right or wrong answers to these questions.

1. Were you employed prior to your diagnosis of cancer? Yes _____ No _____

2. Are you employed now? Yes _____ No _____

Full time _____

Part time (less than 30 hrs. per week) _____

3. Marital Status

Married _____

Single _____

Divorced _____

Other _____ Explain _____

4. Children? Yes _____ No _____

a. If yes, how many do you have? _____

b. If yes, how many still live at home with you? _____

5. Race/ethnicity?

Caucasian _____ African American _____

Latina/Hispanic _____ Asian _____ Other _____ Explain _____

6. Age? _____

7. Level of Education?

Less than high school_____

High School or GED_____

Some College_____

College Graduate_____

Graduate degree_____

8. Family history of Cancer? No_____ **Yes**_____

Type_____

9. Religion/Spirituality? Yes_____ **Explain**_____

No_____ **Explain**_____

10. Date of Breast Cancer Diagnosis _____

11. Type of Breast Cancer _____

12. Type of Treatment _____

APPENDIX D

Interview Guide

Introduction: My name is Margaret Preston on **(date)** with participant **(case#)**. I am going to ask you about your experience related to your diagnosis of breast cancer and any side effects of your cancer treatment. There are no right or wrong answers—I am simply interested in your honest opinions and feelings and thoughts.

1. I'd like to begin by having you tell me your breast cancer story going back to the time of diagnosis.
2. Have you had any appearance-related changes since your breast cancer diagnosis?
 - If so, how have these changes affected you?
3. Were you prepared for any appearance-related changes?
4. Tell me about the importance you placed on appearance investment prior to your diagnosis? For example, did you have your hair done, wear cosmetics, get your brows waxed, use skin care products, etc.
5. Tell me more about your self-esteem prior to your diagnosis? Has your self-esteem changed since your diagnosis and treatment for breast cancer?
6. Can you describe any time you felt the need to hide your cancer to avoid being stigmatized?
 - If so, please explain.
7. How do you feel the following people perceived you during your breast cancer treatment?
 - Your partner
 - Your family
 - Your friends
 - Co-workers, if employed
 - School or recreational activities
 - Grocery store or other public places
8. What was your perception of physical attractiveness prior to your treatment?
 - Related to yourself?
 - Related to your sexuality?
 - Has that changed since the cancer diagnosis and treatment?

- 9. Did any aspect of breast cancer treatment inhibit you from engaging in normal activities? If so, can you please describe?**
- 10. Tell me about your experience related to your social functioning in the following areas:**
 - With your spouse/partner (If you have one)
 - With your family/children
 - With your friends
 - With your church/synagogue (If you have one)
 - With your shopping
 - With your job (If you have one)
- 11. Had any member of your cancer treatment team discussed with you the appearance related side effects of cancer treatment? If so, what were you told?**
- 12. Was it difficult for you to prepare your family for anticipated changes? If so, can you explain? Did anyone guide you?**
- 13. Does it matter to you if people perceive you as someone who has cancer?**
 - If so, please explain.
- 14. Can you describe any experience where you felt insecure about your appearance since your diagnosis?**
- 15. Do you think it is important to address the appearance-related side effects of treatment?**
 - Can you please explain?
- 16. Please describe any aspect of treatment that inhibited your sexual activities?**
- 17. Have you made any changes to your physical appearance since your diagnosis and treatment?**
- 18. What are your thoughts on a cosmetic and grooming behavior clinic as an aspect of treatment for women going through appearance-related side effects of cancer treatment?**
- 19. Would you prefer a one-on-one or a group approach to learning techniques to deal with any appearance-related aspects of cancer treatment? Explain?**
- 20. Tell me about what you think would be helpful to women who are experiencing treatment-related side effects of breast cancer?**
- 21. Were you involved with a social worker during your breast cancer treatment?**

- **If so, what role did the social worker play?**
- 22. Were you involved with any type of psychotherapy/counseling to help you to discuss any psychological discomfort during your breast cancer treatment?**
- **If yes, please explain?**
- 23. What do you think would be helpful for other women to know who have been recently diagnosed with breast cancer in terms of appearance-related side effects of treatment?**
- 24. Is there anything you would like to add?**

APPENDIX E

Participants' Portrait

Tammy

Tammy is a forty-three year old married white female. She was diagnosed with breast cancer at age forty-one. Tammy has two young children and works full-time. She had a double mastectomy last year with LAT flap reconstruction followed by chemotherapy, radiation, and Herceptin. There is no identified family history of breast cancer. Tammy reports that she did have immediate breast reconstruction and increased her bust line one cup size. Tammy identifies spirituality as something that has been important in her life.

Tara

Tara is a forty-three year old married white female. She was diagnosed with breast cancer five years ago with a reoccurrence three years ago. Tara reported having a positive family history of breast cancer which included her sister. She lost her sister from breast cancer while she, herself, was just finishing radiation treatment. Tara had genetic testing after her daughter was born and tested positive for the BRCA1 gene. Tara had a double mastectomy with immediate reconstruction, implants, and oral medication for two years following her first diagnosis. After her second diagnosis Tara had a tumor and 13 lymph nodes removed. Her treatment consisted of four months of chemotherapy, six weeks of radiation, followed by Tamoxifen for five years. Tara has two small children at home. She reports completing some college courses and currently works part-time. Tara reports being spiritual but doesn't attend church. Tara states that she is going to have more breast reconstruction done to correct what she referred to as a "rushed" reconstruction the first time.

Jane

Jane is a forty-one year old, married white female. She was diagnosed with breast cancer five years ago after finding two lumps on her right breast while in the shower. Jane had her right breast and three lymph nodes removed with immediate LAT flap reconstruction and an implant. Jane had four treatments of chemotherapy followed by five years of Tamoxifen. Jane does report a family history of breast cancer which includes her maternal aunt and grandmother. Jane has two children at home. She reported that she cut her hours back at work while going through her breast cancer treatment. Jane is now working a full-time job. Jane identifies as Catholic. She reports that she had five or more breast reconstruction surgeries following her mastectomy that were all cosmetic.

Kathy

Kathy is a forty-two year old married, white female. She was diagnosed with breast cancer following a routine mammogram at age forty. Kathy had two surgeries to make sure the surgeon was able to get clear margins followed by chemotherapy, radiation, and Tamoxifen. Kathy does not have children. She identifies prayer as very important in her life and a way that she was able to find strength throughout her diagnosis and treatment for breast cancer.

Susan

Susan is a fifty-year-old widowed, white, Jewish female. She reported that she was diagnosed with breast cancer at age fifty after finding a lump in her breast while bathing. Susan initially had a lumpectomy followed by a second surgery to remove 12 lymph nodes. The surgeries were followed by four rounds of chemotherapy, thirty radiation treatments, and Tamoxifen. Susan reports that there is no history of breast cancer in her

family. She does not have any children. She was employed at the time of her diagnosis but is not employed now

Jan

Jan is a sixty-five year old, married, white female. She reported an initial diagnosis of breast cancer at age fifty with a re-occurrence four years later. At the time of her first diagnosis she was having her annual mammogram when they discovered a suspicious area. This finding resulted in a lumpectomy and radiation treatments. Several years later she started to notice atrophy in the same breast which doctors attributed to the radiation. When the changes continued she decided to follow-up with her surgeon who confirmed a very large tumor. Jan had a mastectomy, with TRAM flap reconstruction, chemotherapy, and Tamoxifen. Jan has a family history of breast cancer, which includes her mother, maternal grandmother, and niece. Jan has three adult children. She was employed at the time of her diagnosis. She stated that she quit her job following her surgery due to having so many doctor appointments. Jan describes herself as a spiritual person.

Mary

Mary is a fifty-three year old, African American female who identifies as openly gay and in a long-term relationship. She was diagnosed with breast cancer at age fifty-one after finding a lump in her breast. She made a decision to have a double mastectomy with TRAM flap reconstruction. Mary also had fifteen sessions of chemotherapy followed by 28 sessions of radiation. Mary stated that she was unaware of a family history of breast cancer. She identifies her religion as Baptist. Mary worked prior to her diagnosis but does not work now. Mary stated that she is not happy with the results of her reconstruction and would like to have it corrected if she could.

Betty

Betty is a sixty-two year old, married, white female. She was diagnosed with breast cancer at age fifty-one following a routine mammogram. She had a lumpectomy followed by chemotherapy and seven weeks of radiation. Betty is unaware of a family history of breast cancer. Betty has two grown children. She identifies as a religious person who received thoughts and prayers from family members throughout her diagnosis and treatment. Betty states that she worked full time and had a terrific manager who allowed her to work from home. Betty reported that after seven or eight years she was tired of having two different sized breasts and decided to have breast deconstructive surgery which made her feel better.

Karen

Karen is a fifty-seven year old, married, white female. She was diagnosed with breast cancer after a routine mammogram came back with suspicious findings when she was forty-six years old. Karen credits the mammogram with finding the cancer because she did not have a lump that she was aware of at the time. Karen had a mastectomy of her left breast with immediate reconstruction and reduction of her right breast. During the reduction of the right breast the surgeon found that there was also cancer in that breast but he was able to get clear margins. Karen's treatment consisted of chemotherapy, thirty-three rounds of radiation, and Tamoxifen for five years. Karen was unaware of a family history of breast cancer. She was employed full time at time of diagnosis and continues to maintain her full time status. Karen identifies as being a spiritual person. She has four grown children.

Wanda

Wanda is a forty-nine year old, married, Jewish female. She described having a baseline mammogram at age thirty-five and yearly mammograms beginning at age forty. Wanda discovered a lump when adjusting her bra strap. After a series of tests, she was eventually diagnosed with breast cancer. Wanda elected to have a double mastectomy with immediate reconstruction followed by four rounds of chemotherapy. Wanda has three children and works part time for a friend.

Lily

Lily is a fifty-eight year old, separated, African American female. She was diagnosed with breast cancer at age fifty-two after finding a lump on her right breast. Lily had a lumpectomy followed by chemotherapy, radiation, Tamoxifen, and Arimidex. Lily identifies an aunt who was also diagnosed with breast cancer. Lily worked full time prior to her diagnosis and treatment; however, due to the development of Lymphedema she had to go on disability. Lily has three grown sons. She describes herself as a religious person who attends a Baptist church regularly.

Lauren

Lauren is a fifty-eight year old, married, white female. She discovered her breast cancer during a routine mammogram at age forty-eight. Lauren elected to have a Lumpectomy, lymph node dissection, and radiation followed by Tamoxifen then Arimidex. Lauren worked full time throughout her diagnosis and treatment for breast cancer. She has three grown children. Lauren describes herself as a Catholic.

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