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BODY IMAGE AS PERCEIVED BY WOMEN TREATED FOR BREAST CANCER

BY

MIRI ROBSON ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of DOCTOR OF PHILOSOPHY

IN

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Abstract

Breast cancer simultaneously threatens a woman's life and disrupts her physical integrity, often in starkly visible ways. The woman is faced with the challenge of integrating these physical changes into her self-image. How a woman views her body plays a key role in determining psychological adjustment and quality of life after treatment for breast cancer. The purpose of this study is to explore through qualitative methodology, women's unique perception of their altered bodies after experiencing breast cancer. Eight pre-menopausal women (under the age of 50), who had finished different treatment modalities for at least one year, and had no evidence of metastatic disease, participated in the study. In depth interviews were conducted and the data were analyzed in accordance with hermeneutic-phenomenological methodology. The data revealed several interrelated themes which although subjectively defined, were often communally shared. These themes include: body image as a personal perspective; the body as a physical experience - incorporates the body as an object and functioning instrument; the public body - includes the visible and observed body; the private body as an expression of self - refers to issues related to feminine identity, intimacy and sexuality; and reintegrating body image into the self. The findings of the study revealed that participants were grieving not solely for the physical changes that have occurred to their bodies, but also to a change of self-perception both in body image and identity. An understanding of women's unique responses to the changes in body image after treatment for breast cancer, can help health care professionals assist women in integrating the body changes into their self and improve quality of life.

UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled BODY IMAGE AS PERCEIVED BY WOMEN TREATED FOR BREAST CANCER submitted by MIRI ROBSON in partial fulfillment for the degree of DOCTOR OF PHILOSOPHY in COUNSELLING PSYCHOLOGY.

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CHAPTER ONE

INTRODUCTION

Breast cancer is the most common form of cancer among women. During their lifetimes, one in nine women will develop the disease (National Cancer Institute of Canada, 1998). While an exact understanding of the causes and control of breast cancer continues to elude researchers, rapid advances in detection and treatment have led to increases in the disease-free survival among women diagnosed with breast cancer (Rowland & Massie, 1998). However, unlike the treatments for other chronic diseases, the treatments for cancer are both more toxic and intensive. The result is increasing demands not only on patients' physical reserves, but also on their psychological and social resources to survive and manage the illness (Rowland & Massie).

Breast cancer simultaneously threatens a woman's life and disrupts her physical integrity, often in starkly visible ways. A diagnosis of breast cancer becomes not only a health crisis, but a deeply disturbing emotional crisis that challenges a woman's identity as a woman. This cancer threatens an organ of the body that is intimately associated with self-esteem, sexuality, and femininity. These are psychological issues of paramount concern to ill and healthy women alike and may serve to explain the plethora of research which has been undertaken into the psychosocial aspects of breast cancer.

Psychosocial research on breast cancer has reported on the concerns of women undergoing treatment for the disease. Surgery, radiation therapy, and chemotherapy in varying combinations are used in the treatment of breast cancer. The body which is diagnosed as diseased is subjected to disfiguring surgery, followed by treatments that can, for example, burn the skin, denude it of hair, and render it infertile. The woman to whom this body belongs is faced with the challenge of integrating these physical changes into her self-image. How a woman views her body plays a key role in determining psychological adjustment and quality of life after treatment for breast cancer (Schain, 1997). Studies report that in two areas of psychosocial functioning - body image and sexuality - problems do not appear to abate over time, even for disease free patients who are well adjusted in other domains (Schag, Ganz & Polinsky 1993). Consequently, body image has frequently been included in many studies of survivors in order to assess the long term psychological impact of these injuries to the body (Fallowfield & Hall, 1991; Hopwood & Maguire, 1988; Kiebert, de Haes & Van de Velde 1991; Mock, 1993; Schover, 1991; Vinokur, 1990).

Substantial research has examined the effects of specific surgical treatments and has compared the degree of dysfunction among these treatment alternatives with some conflicting results (e.g., Ganz, Schag, Lee, Polinsky & Tan, 1992; Lasry & Margolese, 1992; Levy, Haynes, Herberman, Lee & Kirkwood, 1992; Margolis, Goodman & Rubin, 1990; Noguchi, Katagawa & Kinoshita, 1993; Schain, d'angelo, Dunn, Lichter & Pierce, 1995). Given the importance of the breast to women's sense of femininity and its role in sexual relationships, mastectomy and breast-conserving treatment have been the most heavily studied treatments of all in terms of their impact upon body image and related psychosocial and sexual functioning. In comparison, less research has been conducted to examine the effects of other treatments modalities, like chemotherapy and radiation, on body image. In addition, much of the research to date has been guided by a medical model that focused on surgery procedures which are used for amputation and possible restoration of a body part (Fallowfield & Hall, 1991; Kasper, 1994). This narrow focus ignores the larger issue of living with a body that has been altered and treated for a life threatening disease.

Most of the existing literature on women's adjustment to breast cancer is aimed at obtaining information about physical or psychological symptoms so as to measure their impact. Measurements included the use of "body image" questionnaires or items from such questionnaires, which originally have been developed for use in the general population (Ben-Tovim & Walker, 1991; Brown, Cach & Matikula, 1990; Secord & Jourard, 1953). These measures concentrate on satisfaction with body parts or general appearance and their value has been in identifying key areas amenable to assessment by self-report questionnaires, but they fail to sample areas of salience to women with breast cancer (Baxter, Goodwin, McLeod, & Devins, 1997; Ganz, Rowland, Desmond, Meyerowitz & Wyatt, 1998). Women's own stories can not be fully captured by fixed choice questionnaires, in which they choose a response that may not fully represent their experience. Women speaking for themselves have repeatedly highlighted the psychological and cultural meaning of their body cues (Fallowfield & Hall, 1991). In Mathieson's (1994) research on women and cancer, she concluded that "had I stuck with standardized questionnaires only, I would have had body image scores which in no way address the meaning of body image changes for women with cancer" (p.16). Therefore, an exploration of body image that was affected by breast cancer, must utilize a methodology that maximizes the informant's point of view, and captures this information in context (Kasper, 1994).

Fallowfield (1990), who conducted several studies on body image and breast cancer, further criticized studies that collect their data through the use of questionnaires. She pointed out that many of these questions are ambiguous and confusing. Some questions blur the distinction between what the woman feels for herself and how she feels others respond towards her. In addition, most studies do not specifically ask about body image prior to surgery, so that it is unclear as to whether body image changes are a consequence of diagnosis and treatment.

Central to the methodology of this study is the belief that the essential meanings of women's lives can be grasped only by listening to the women themselves. Participants in this study were given the opportunity to describe their unique perception of the changes that occurred to their body as a result of the different treatments for breast cancer. These include the wide range of surgical, chemotherapeutic, and radiation therapies which alter the body and can leave permanent damage. They were also given the opportunity to describe their body image prior to the diagnosis of cancer. An holistic and comprehensive view was obtained from the women themselves without the constriction of the questionnaire approach.

A sample of eight premenopausal women, who had finished treatment for at least one year, and had no evidence of metastatic disease, participated in the present study. Research conducted on body image and breast cancer revealed that women whose cancer has metastasized are more likely to be concerned with existential issues than with body image concerns (Kornblith, 1998). Therefore, this study focused on women with no evidence of metastatic disease. Existing research also suggested that investigations of body image may not yield valid results if they are conducted immediately after surgery (Glanz & Lerman, 1992; Penman, Bloom, Fotopoulos, Cook & Holland, 1987; Polivy, 1977; Taylor, Lichtman, Wood, Blumming & Leibowitz, 1985). Therefore, the present study focused on women who had completed treatment for at least one year. Additional research revealed that breast cancer patients manifest age-related differences in the psychosocial impact of their illness (Mor, Malin & Allen, 1994; Rowland & Massie, 1998; Siegel, Gluhosky & Gorey, 1999; Vinokur, 1990). Younger breast cancer patients report high levels of emotional distress regarding their bodily changes, which is related to specific issues associated with their developmental age (Mor, et al.). As well, younger women with breast cancer are treated with chemotherapy much more frequently than older women (Siegel et al.). Consequently, they are more likely to endure the possible side-effects caused by this treatment. Ganz, Rowland, Desmond , Meyerowitz, and Wyatt (1998) pointed out that with the increasing use of adjuvant chemotherapy in younger women with early stage breast cancer, the long term impact on the changes in their perceived body image and sexual attractiveness must be a high priority for research. In this study women participants were premenopausal (under the age of 50) at time of diagnosis.

The present study asks the questions: How do women experience their altered bodies after being diagnosed and treated for breast cancer? How do women manage the threats to body image and identity and come to a resolution of the crisis in ways which preserve or redefine their understanding of themselves as women? A phenomenological hermeneutic approach within a qualitative methodology was employed in this study to elicit women's experiences and perceptions of their altered bodies. A thematic analysis was used to describe and interpret their stories.

The purpose of the study was to gather information that would add knowledge and in-depth understanding of women's perception of their bodies after treatment for breast cancer. This knowledge provides the added dimension of women's perspective to the current literature. It is also clinically relevant and may potentially be applicable by physicians and mental health professionals who work with these women and assist them in managing their illness and improve quality of life.

Although each woman's perception of her altered body is unique, there were commonalties in their experiences. It is my belief that enabling these women to share their experiences with the larger population of women who experience breast cancer, can help reduce their suffering and the suffering of others. Understanding the essence of altered body image from the time women receive the diagnosis, provides other women with breast cancer with information that may help to validate their own experiences.

Organization of the study

This first chapter outlined the problem and addressed the significance and purpose of the study. Chapter two identifies the theory of body image as part of the self, which provide the framework of this study. It also discusses the relevance of the research question in the context of a literature review. Chapter three provides a discussion of the methodology employed in the construction of the data and the subsequent analysis and writing of the findings. A description of phenomenological-hermeneutic methodology which was employed in the study was outlined. Included are research procedures such as selecting participants, acquiring the data, and data analysis. This chapter concludes with a discussion on trustworthiness and ethical considerations. Chapter four presents the findings of the study. Themes that emerged from the analysis of the data are described and illustrated with quotations from the participants' stories. In chapter five, the findings are discussed in conjunction with the current literature and research. Finally, implications and limitations of this study and directions for future research are outlined.

CHAPTER TWO

THEORY AND RESEARCH

Anyone who becomes ill or sustains an injury experiences some form of change and loss, such as changes or loss of mental or physical function, level of independence, self-image, identity, and body image. The latter is the focus of this study specifically related to breast cancer.

Self-concept is a significant factor in the recovery and rehabilitation of the person with cancer. Aspects of cancer (e.g. uncertainty regarding its etiology and course) and cancer treatment (e.g. the aggressiveness of many therapies) serve to make patients and survivors particularly vulnerable to changes in their self views. Body image is an integral component of self-concept. Cancer, its treatment, and resulting changes in appearance, abilities, and function often cause a change in body image and can negatively affect the person's self-concept (Derogatis, 1986; Dudas, 1993; Foltz, 1987). An understanding of body image as a component of self-concept, can aid in understanding how women with breast cancer manage their altered body image and integrate the changes into their self-concept.

The purpose of this chapter is to examine existing literature and research relevant to the exploration of body image and breast cancer. It provides an overview of the theoretical notion of body image as a component of self-concept, focusing on changes in body image after disease and injury and specifically after diagnosis of breast cancer. The nature and treatment of breast cancer is outlined. Medical, psychological, and sociocultural, factors affecting women's responses to body image changes in breast cancer are addressed.

Body Image as a Component of Self-Concept.

Self-concept is the total perception an individual holds on self: who one believes one is, how one believes one looks, and how one feels about one's self. Self-concept influences the way an individual perceives the world and interact with it (Fitts, 1971).

A comprehensive definition of the self-concept is adapted from Roy (1976) who viewed self-concept as "the composite of thoughts, values, and feelings that one has for one's physical and personal self at any given time, formed from interactions with the environment and with other people, and directing one's behavior" (p.169). Self-concept is viewed as being the result of life-time of social interactions and experiences, which serve as the basis for the evaluation of one's appearance, background, abilities, resources, attitudes, and feelings. In this model, the self-concept is considered an adaptive mode with two components: a physical self and a personal self. The physical self is sensed through sensorimotor experiences and includes physical being, attributes and functioning, sexuality, and wellness-illness states. Problems in the physical self are experienced as loss. The personal self is composed of the moral-ethical self, the self-consistency self, and the self-ideal self. The moral-ethical self functions as an observer, standard-setter and evaluator of behavior, influencing the self-esteem. The self-consistency self maintains a stable self image, whereas the self-ideal self is concerned with what one wants to do or expects to become. Problems in these subselves are experienced as guilt, anxiety, and powerlessness. The total self-concept is the result of the perception of responses by others (especially significant others), developmental tasks and crises, and genetic and environmental factors.

Body image is closely related to self-concept, identity, and self-esteem (Champion, Austin & Tseng, 1982; Curbow, Somerfield, Legro & Sonnega, 1990; Drench, 1994; Foltz, 1987). As a component of self-concept, the body is the structural, functional, and visible part of the self that encloses the self-concept and allows interactions with the environment and other people (LeMone, 1991). It is the portion of the self-concept relating to the psychological representation of the body or the physical self (Vamos 1993). As body image and self-concept are closely associated, a loss of or alteration in any one of these factors can have deleterious effects on the entire self (Bramble, 1990).

Body Image Theory

Body image is a construct relating both to actual body experience and also to the psychological interpretation of this experience, thus the body image is the way our body appears to ourselves as a mental image (Janelli, 1986).

The concept of body image was first described in terms of postural and body movements and was viewed within a neurological framework: a person's self-image was represented neurologically in the brain (Head, 1920). It was further developed to include psychological constructs. Schilder (1950) built on Head's theory by including the person's personal investment in various body parts and environmental influences as factors influencing body image. He proposed that people form a picture of their body appearance within their minds. This picture includes interpersonal, environmental, and temporal factors. His theory holds that the development of body image is continuous, active, and affected by physiological, psychological, and sociological factors. The contemporary idea of body image incorporates a wide range of psychosocial aspects and deals not only with how people actually look, but how they think they look. As such, body image is part of the self-concept that involves attitudes and experiences pertaining to the body, including notions about masculinity and femininity, physical prowess, endurance, and capabilities (Drench, 1994).

Pruzinsky and Cash (1990) have identified seven integrative themes in body image development, deviance, and change. These themes can be summarized as follows:

Theme 1. Body image refers to perceptions, thoughts, and feelings about the body and bodily experience.

We have many perceptions, thoughts, and feelings about our body: its overall appearance, specific features or parts, age, ethnicity, strength, body functions, sexuality, etc. A central aspect of this theme is that body image is a highly personalized or subjective experience. There is no necessary correlation between subjective experience and "objective" reality. Thus, the individual's subjective impression or experience of the body is not necessary congruent with the individual's body.

Theme 2. Body image is multifaceted.

Implicit in the first theme is the second - that body image is multifaceted. Shontz (1990) describes seven functions performed by the body-image construct. They include: a sensory register, an instrument for action, a source of drives, a stimulus to the self, a stimulus to others, a private world, and an expressive instrument. Additionally, Fisher (1986) concludes that there is no such singular term "the body image". Extant research clearly indicates that body experience encompasses the perception of and attitude toward appearance, body size, body spatial position, body boundaries, body competence, and the gender-related aspects of one's body. An individual's attention can move from one of these components to another, or simultaneously be at one or more levels.

Theme 3. Body-image experiences are intertwined with feelings about the self.

How we experience our bodies significantly relates to how we perceive ourselves. The sense of self is based on the experience that one is embodied and differentiated from the outside world and from others. If one has negative body-image attitudes, then one is vulnerable to negative experiences of the self as a whole. Conversely, it is also the case that persons sometimes project blame into the body for perceived deficiencies in other aspects of the self (Cash, 1990).

Theme 4. Body images are socially determined.

The development of body image is based on interactions with our primary caretakers. The initial years with parents almost exclusively involve interacting in terms of bodily functions. How these bodily functions are handled can set an important emotional tone for our incipient experiences of our bodies and ourselves (Fisher, 1986). The social influences on body image continue throughout life. Culturally validated definitions of what is desirable and attractive play an important part in the development of body image. One's body image includes his/her perception of the cultural standards, his/her perception of the extent to which he/she matches the standard, and the perception of the relative importance that members of the cultural group and the individual place on that match (Fallon, 1990).

Theme 5. Body images are not fixed or static.

Aspects of our body experience are constantly changing. All body image experiences must be understood from a developmental perspective (Lerner & Jovanovic, 1990). Our bodies change as we grow and age, and each developmental stage has its associated markers. These physical attributes often have salient cultural meanings and entail standards for social evaluation and for internalized self-evaluation (Fisher, 1986). Childhood brings about drastic changes in size and strength. Adolescence brings about many physical changes that facilitate the development of sexual functioning. Middle age and old age bring along a decline in physical stamina, as well as appearance changes (Janelli, 1986). Furthermore, there are both gradual and abrupt changes in the body and body images. Gradual changes in the body are more easy to psychologically accommodate than abrupt changes. Despite a negative evaluation of changes associated with aging, most individuals are able to come to terms with them. However, if an individual is suddenly confronted with abrupt body change, the psychological reaction can be much more disruptive (Drench, 1994).

Theme 6. Body images influence information processing.

How we feel and think of our body influences the way we perceive the world (Fisher, 1986). Bodily self-conscious persons allocate large portions of their daily attention on this one aspect of their existence. Furthermore, social events that may not be related to the person's appearance are interpreted in terms of the individual's appearance.

Theme 7. Body images influence behavior.

An individual's conscious and unconscious body image influence behavior, particularly interpersonal relationships (Fisher, 1986). For example, not only do physically attractive persons have advantages in their social worlds, but having the belief that one is attractive also fosters social confidence and skill (Pruzinsky & Cash, 1990). On the other hand, individuals with deformity are more likely to be socially withdrawn and inhibited. In turn, such processes can exert a subsequent adverse impact on the overall self-concept.

From experiences that begin in childhood, individuals learn to place different values on various parts of their body (Fisher, 1986). Some body parts are highly valued and may be highlighted by body posture. Hair styling, cosmetics, and clothing may be selected to display these body parts. Cosmetic use, as well as other grooming behaviors serve also as motivated efforts to cope with or compensate for specific disliked body features. The valuing of particular body parts varies to some extent from one person to another, from one culture or religion to another, and from one period of time to another (Fisher).

Changes in Body Image After Disease and Injury.

When body integrity is breached or body function altered, it can alter the perception of body image and interfere with the entire self-concept including interrupting social and vocational roles (Bronheim, Strain & Biller, 1991). Changes in body image after disease or injury can significantly harm a person's whole identity. When a person grieves and mourns, it is not solely for the physical loss of body integrity but also for the loss of the intact self.

The concept of disturbances in body image has been studied in depth by Kolb (1975). He identified a series of emotional, perceptual, and psychosocial reactions to alterations in the body. He believed that the nature of these reactions determines whether the individual's adaptation is healthy or pathological. Whether a negative change in the body image results from a surgical procedure or from some other cause, it always arouses anxiety in the patient. The distortion of the customary body image is experienced as a distortion of the self. Further anxiety may result as disfigured individuals are threatened by fears of rejection and separation from the significant persons upon they are dependent. Reactions to body image disturbances are basically dependent upon the meaning of the bodily defect to the individual and significant others (Kolb).

The wish to be well and intact is very compelling; any alteration or loss as a result of illness becomes a danger to the self. If the relationship between a whole body and the essence of the self is strong, changes may not be able to be integrated into the self-concept. Perceived negative changes in body image are met with strong resistance, especially when they devalue self-esteem. This resistance is influenced largely by the meaning of the physical alteration to the individual and, secondarily, by the consequences of these physical changes (Drench, 1994). The phantom limb phenomenon is an illusion that a body part that has been removed still exists in the patient mind. Individuals who have had amputations experience the phantom limb because of a compelling need to maintain an intact body image and because of real physical sensations (Schoenberg & Carr, 1970).

Bodily appearance serves as an expression of identity of the self to others. In a society that places high value on physical attractiveness and prowess, it is difficult to accept physical disability with its psychosocial overlay. Depending on the degree to which physical appearance is linked with self-esteem, the person may loose more than the obvious physical factor. To an individual whose body image is highly valued within the self-concept, acceptance of a physical disability may be strongly resisted because it would present too much danger to the self-concept. A person whose body image is not a key to self-concept, will be better able to assess circumstances realistically and make the necessary modifications.

Cancer and Body Image

Cancer, its treatment, and resulting changes in appearance, abilities, and function often cause a change in body image and can negatively affect a person's self-esteem (Dudas, 1993). Such body image changes are viewed as threats or major losses. Reality for that person has changed, and uncertainty has increased. The patient must then determine the personal meaning of the body alteration and evaluate the reaction of his/her social support system to the body change. All of these changes must then be integrated within the self structure, with an acceptance of "this is who I am". When patients fail to adapt to loss of a body part or a body function as a result of cancer treatment, their quality of life during survival may be severely compromised. Failure to integrate body image changes is associated with long term depression, difficulty in interpersonal interactions, withdrawal from social interaction, and overall a lower quality of life (deHaes, Van Oostrom & Welvart, 1986; Dudas, 1993; Krouse & Krouse, 1981). This outcome can be life-threatening for persons with cancer in that these persons may choose not to continue treatment. For such individuals, the body image change seem to be even more important than life itself. The depression, lack of energy, and the perceived changes in view of the self, leave little strength for participating in the fight for life (Burns & Holmes, 1996).

Certain types of cancer are more likely to affect body image. Breast cancer and its treatment is a major cancer associated with altered body image. Loss of a body part that is significantly related to feminine identity can result in a negative alteration in body image and self concept (Burns & Holmes, 1996).

The following section provides an overview of the nature and treatment of breast cancer. A review of the literature pertaining to body image and breast cancer will follow.

Cancer, Breast Cancer, and Breast Cancer Treatments

What is Cancer?

Cancer is a general term for the abnormal growth of cells. In general, the earliest pathological transformation of a tissue from normal is presented by an exuberant overgrowth of normal-appearing cells. Eventually, some of the cells will develop atypical features (e.g., they look more abnormal and begin to develop some features of cancer cells). Further along this continuum of tissue transformation are highly abnormal-looking cells and a state called "in situ cancer". In this latter situation, there is a localized growth of malignant cells that does not invade the adjacent tissue.

In situ cancers are low-grade malignancies because they rarely "metastasize" (spread to distant parts of the body). When the malignant cells frankly invade the adjacent tissue, this is a true cancer. Under these circumstances, the prognosis is directly related to the size or dimensions of the primary tumor and the extent to which it has spread to local lymph nodes or distant organs (Ganz, 1998).

The entire process described in the preceding paragraph takes decades to occur under most circumstances. Cancer is a multistep process that requires a series of critical insults to the DNA of a cell. It may take 20 -30 years for a known carcinogen to cause sufficient damage to a tissue to force the cells through the phases and become *in situ* cancer. Finally, when the first cancer cell develops, it may take another 8 -10 years of repeated doubling of the cells before the tumor reaches the size that is detectable with screening (e.g., by mammography).

Breast Cancer

Breast cancer is the most common malignancy in women (National Cancer Institute, 1998). In general, some form of "staging" is performed for most cancers. Stage is directly related to prognosis and determines the type of treatment to be offered, especially when several therapies are available. The TNM classification system is used to stage breast cancer according to the size of the primary tumor (T), the involvement of the lymph nodes in the armpit (axillary nodes) next to the affected breast (N) and the presence or absence of metastases (M). The clinical stages range from stage I to IV (Ganz, 1998).

The prognosis and selection of therapy are influenced by the size, type and stage of the cancer, the microscopic appearance and tumor grade, the involvement of the axillary (armpit) lymph nodes involved, and the woman's age and her menopausal status at the time of diagnosis. The larger the cancer, the more likely it has spread to axillary lymph nodes and metastasized. In the present study, women participants were at stage I to III, and had no evidence of metastatic disease.

Treatment overview

It is now a standard practice for primary physicians, surgeons, radiation oncologists, and medical oncologists to work together to plan and carry out a treatment plan. The basic principle of breast cancer treatment is to remove the identifiable cancer and a rim surrounding normal tissue to make sure that there is a "margin" of safety around the tumor. Studies performed during the last 10-15 years have demonstrated that there is no difference in survival between breast-conserving surgery, also called lumpectomy (removal of the breast tumor and lymph node dissection) followed by radiation therapy, and total mastectomy (removal of the entire breast and lymph nodes). A woman who either chooses or requires a total mastectomy can be offered surgical reconstruction of the breast (Ganz, 1998).

After surgical treatment, a decision will be made about subsequent treatment (adjuvant therapy). If the tumor is very small, no further therapy may be required. Some women may require adjuvant therapy with the antiestrogen tamoxifen; others may require radiation therapy, or chemotherapy treatment; and some may be given both. Overall, a woman with a diagnosis of breast cancer can anticipate some form of additional therapy after surgery, and the intensity of the therapy will relate to her risk of recurrence.

Post-mastectomy breast reconstruction is an elective procedure to reconstruct the breast that has been removed. Surgeons have devised a number of reconstructive procedures to replace the breast. These options are generally of two types: either reconstruction with an implant or the use of the woman's own tissue known as autogenous tissue reconstruction. Artificial implants can be either silicone or a saline-filled sac, often preceded by the use of a temporary tissue expander to prepare the chest area to receive the implant. There are several methods of reconstruction using the woman's own tissue, all of them involving "flaps". Skin, muscle, and fat are taken from either the back or the abdomen - also known as the TRAM (transverse rectus abdominis myocutaneous) flap. In this procedure the surgeon removes the rectus muscle from its site in the abdomen, tunnels it under abdominal tissue, and brings the rectus muscle into place on the woman's chest, trimming and shaping it to approximate the lost breast (Stoppard, 1996).

In the present study participants had stage I to stage III breast cancer with no evidence of metastatic disease. One woman chose to have a saline implant and one had a TRAM flap reconstruction. Following this brief overview of the nature of breast cancer and it's treatments, a review of the related literature and research on breast cancer and body image is explored.

Body Image and Breast Cancer

Of the numerous types of cancer that affect body image, breast cancer has been the most frequently studied (Irvine, 1996). Breast cancer simultaneously threatens a woman's life and disrupts her physical integrity, often in starkly visible ways. In

Western cultures, breasts are associated with femininity, sexuality and self-esteem (Fallowfield, 1996; Rowland & Massie, 1998). Therefore, a diagnosis of breast cancer becomes not only a health crisis, but has the potential of becoming a deeply disturbing emotional crisis that challenges a woman's body image and identity as a woman (Kasper, 1995). Studies report that in two areas of psychosocial functioning - body image and sexuality - for some women, problems do not appear to abate over time, even for disease free patients who are well adjusted in other domains (Schag, Ganz & Polinsky, 1993).

While breast cancer is a major stress for any woman, there is great variability in women's psychological responses and adaptation. Three sets of factors contribute to psychological response to body image changes in breast cancer:

1. The medical factors or physical facts the woman must confront in terms of disease-stage, treatment, response, and clinical course.
2. The psychological and psychosocial factors that the woman and her environment bring to the situation.
3. The sociocultural context within which cancer occurs and can affect how patients view themselves, their illness, and future.

Medical factors

The stage of breast cancer at diagnosis, the treatment required, the prognosis and the rehabilitative opportunities available constitute the medical factors that influence psychological response to body image changes. The following section will focus on the treatment effects on body image.

There is considerable evidence that the wide range of surgical, chemotherapeutic, and radiation therapies can leave permanent damage to organs and physiological functioning and cause disfigurement (Kornblith, 1998). Substantial research has examined the effects of specific breast cancer treatments on body image and has compared the degree of dysfunction among these treatment alternatives. The most obvious of these are the mutilating effects of surgery (Ganz et al., 1992; Kiebert, de Haes, van de Velde, 1991; Lasry, Margolese & Poisson, 1992; Levy, et al., 1992). Radiotherapy often leads to such consequences as changes in the texture of the breast tissue and the contour of the breast, thickening of the skin, and discoloration of the skin, all of which alter body image (McCormick, Yahalom, Cox, Shank & Massie, 1989). Patients receiving chemotherapy may experience alopecia, weight gain, and premature ovarian failure (Baxley, Erdman, Henry & Roof, 1984; Demark-Wahnefried, Winer & Rimer, 1993; Freedman, 1994; Humble, 1995; Pickard-Holley, 1995, Schover, Yetman & Tauson, 1995). These side effects often affect body image.

Mastectomy, Lumpectomy and their effect on Body Image.

Prior to the availability of breast-conserving surgeries, it was widely believed that the disfigurement caused by mastectomy was the primary cause of distress and disruption for breast cancer patients. This belief led to the expectation that breast-conserving surgeries would prevent most of the problems experienced by patients (Rowland & Massie, 1998; Schover, et al., 1995). However, post-treatment data from over two dozen studies have found few differences between the two groups with respect to psychosocial and emotional functioning. Both groups had equivalent psychological distress, fear of recurrence, and overall psychosocial adjustment

(Fallowfield, 1990; Ganz, Schag, Lee, Polinsky & Tan, 1992; Kiebert, de Haes, Van de Velde, 1991; Levy et al., 1992; Schain, d'angelo, Dunn, Lichter & Pierce, 1995; Schover, Yetman & Tauson, 1995). Given the expected emotional benefit that saving the breast was expected to provide women, some have argued that the differences seen between the groups are less than intuitively expected (Fallowfield, 1996; Glanz, & Lerman, 1992).

Despite the similarities between the surgeries in their effects upon psychological adjustment and quality of life, there appear to be evidence for differences in effects upon body image and sexuality. Women who have had conservative surgeries consistently report better body image (Ganz, Schag, Lee, Poloinsky & Tan, 1992; Hall & Fallowfield, 1989). These women feel more comfortable with their appearance and have fewer concerns about finding attractive clothes (Ganz et al., 1992; Noguchi, Katagawa & Kinoshita, 1993). Some studies (Wolberg, Romsaan, Tanner & Malec, 1989) demonstrated that women who have had conservative surgeries also show advantages in terms of sexual satisfaction and functioning. On the other hand, women who have had conservative surgery with radiation treatment report greater difficulties in regard to cosmetic problems (Ganz et al., 1992).

There is considerable research which has reported on the impact of mastectomy on women's body image and related psychosocial and sexual functioning (Fallowfield, 1990; Kiebert, de Haes & van de Velde, 1991; Schover, Yetman & Tauson, 1995). Among the effects documented are feelings of mutilation and altered body image, diminished self-worth, loss of a sense of femininity, decrease in sexual attractiveness, anxiety, shame, and abandonment (Hopwood & Maguire, 1988; Penman et al., 1987; Polivy, 1977). Distress over scars, feelings of being less sexually attractive, and being uncomfortable in more revealing clothes such as bathing suits (Polinsky, 1994; Wellisch, 1985) and therefore avoiding leisure activities that necessitated this exposure were common expressions of body image problems. Not surprisingly, a poorer body image was significantly related to worse adjustment (Schover et al., 1995).

Other studies found that women who had a mastectomy can continue to experience emotional distress over issues related to body image, and these problems do not seem to abate over time (Ferrans, 1994; Ganz et al., 1996; Lasry, Margolese & Poisson, 1987; Polinsky, 1994; Schag, Ganz & Polinsky, 1993). However, even women who had only breast-conserving surgery were found to have body image problems, with those reporting edema of the arm having significantly worse body image (Fallowfield, 1991).

Reconstruction and Body Image.

Because of advances in plastic and reconstructive surgery, breast reconstruction is an option for women who underwent mastectomy. The goal is to provide symmetry and preserve body image (Dudas, 1993). Women choose reconstruction in order to eliminate the need for an external prosthesis and to be able to wear more attractive clothing. Other reasons for choosing reconstruction were to increase self-esteem and to improve their appearance (Schain, 1991).

A substantial majority of women report being satisfied with the cosmetic results of reconstructive surgery (Schain, 1991; Rowland, Holland, Chaglassian & Kinne, 1993). Some women also experience positive effects in other domains, such as body image and psychological adjustment (Mock, 1993; Pozo, Carver & Noriega, 1992; Rowland et al., 1993; Schain, 1991). While most women who choose reconstruction seem to benefit from it, they do not appear to experience psychological advantages relative to other breast cancer patients. Women who have had breast reconstruction do not report better psychological adjustment, body image satisfaction, or sexual functioning compared to women who did not have breast reconstruction (Reaby, Hort & Vandevold, 1994; Rowland & Holland, 1998). Moreover, in comparison to women who have breast-conserving surgeries, women who undergo immediate reconstruction report worse body image and less patient satisfaction (Mock, 1993; Noguchi, Katagwa & Kinoshita, 1993). In addition, removal of tissue from the abdomen or back to reconstruct the breast leaves some patients with concerns about scarring and pain (Noguchi et al., 1993).

Chemotherapy, Radiation and Body Image.

The news that adjuvant chemotherapy is required for the recovery demands psychological adjustment to yet another treatment modality. This involves a lengthened treatment period, but implicit in the need for systemic therapy is the awareness that breast cancer is a threat to life. Meyerowitz, Watkins & Sparks (1983) studied women with breast cancer during chemotherapy and two years after completing it. Among those disease free at two years, 23 percent reported difficulty with personal and family relationships during treatment, and 44 percent had continuing physical problems two years later.

Side effects of chemotherapy and radiation treatment may cause distressing symptoms that interfere with the woman's body image. These include hair loss, weight gain, fatigue, muscle atrophy and neurological changes (Dudas, 1993). While anticipated, the impact of alopecia is often devastating (Baxley, Erdaman, Henry & Roof, 1984). Some women report this as more distressing than the breast surgery itself, in part because it is a visible indicator of disease but also because it is overtly disfiguring (Freedman, 1994). The cause of weight gain remains unclear (Denmark-Wahnefried, Winer & Rimer, 1993), however it poses an added insult to self-esteem and body image.

A final troublesome effect of chemotherapy in younger women is premature ovarian failure (Schover, 1994). The threatened or actual loss of fertility and acute onset of menopausal symptoms anticipated with adjuvant treatment, often causes distress in the woman who is premenopausal at diagnosis. The hot flashes, nightsweats, and vaginal dryness and atrophy caused by chemotherapy induced menopause produce severe discomfort, and affect body image and sexuality (Schover, Yetman & Tauson, 1995).

The above extensive research review indicates that there is considerable evidence that the different treatment modalities for breast cancer have significant effect on women's body image and self-esteem. However, this research often reported conflicting results and may not have captured important information pertaining to women's individual perception of their disease. The present study explored women's holistic perception of the effect the treatments had on their bodies and how they integrated these changes into their lives.

Psychological factors

Important factors which determine psychological response to body image changes in breast cancer include: the life stage at which the cancer occurs, previous emotional stability (personality and coping style) and personal history, the presence and availability of interpersonal support (Rowland & Massie, 1998).

In evaluating the psychological response of breast cancer patients, it is important to consider the developmental stage of the woman (Rowland & Holland, 1990). The developmental stage is where the person is with respect to life cycle-related biological, personal, and social life goals and tasks when cancer occurs. Information about the time at which cancer occurs in the life cycle, and what tasks are threatened or interrupted as a consequence, provide insight and understanding of women's perception of their body image following diagnosis of breast cancer.

A number of studies suggest that younger women diagnosed with breast cancer experience more adaptational difficulties than do older women (Ganz, Schag, Lee, Olinsky & Tan, 1992; Mor, Mallin & allen, 1994; Northhouse, 1994; Siegel, Gluhosky, & Corey, 1999; Vinokur, 1990). Several significant tasks for young women are likely to be affected by a diagnosis of breast cancer (Siegel et al., 1999). Women at this stage often merge their identity with a significant other and make long-term commitments. In addition, because procreation usually occurs at this time, breast cancer may impair the continuation of intimate relationships when the disease and its treatment produce concerns about physical attractiveness or feelings of desirability. These concerns may be especially intense among women who feel disfigured by the disease, among those who fear that conception may increase the risk of recurrence, or among those whose fertility has been compromised or lost as a result of treatment (Siegel et al., 1999). The threat to a sense of femininity and self-esteem occurs in all women, but it may be more difficult to a young woman whose attractiveness and fertility are paramount, especially for those who are single and without a partner (Mor et al., 1994; Norhthouse, 1994). The present study focused on women who were premenopausal at time of diagnosis (under age 50).

A woman's adaptation and response to diagnosis of breast cancer relates to her personality and coping patterns. Women with pre-existing psychological morbidity are likely to experience emotional problems on diagnosis and through treatment and survivorship (Rowland & Massie, 1998). Some women with a high investment in their body's appearance are at a higher risk for problems in adaptation following treatment, particularly if hoped-for attempts to preserve cosmetic appearance are less successful than expected or must be abandoned because of the extent of the disease (Fallowfield, 1996; Rowland & Massie, 1998).

Adjustment to changes in appearance, structure, or function of the body depends also on the response from other significant people - first and foremost from spouse or partner- but also from family and friends (Maunsell, Brisson & Deschenes, 1995, Northhouse, 1994, Vinokur, 1990). The husband, or partner, is often the first person called upon to provide emotional support to the women undergoing mastectomy. A study by Wellisch (1985) indicated that for thirty six percent of partners, sexuality and intimacy have been altered. Some males reported distorted perceptions related to the image of their partner's body after surgery. Two studies have suggested that spouses of women undergoing mastectomy have greater adjustment difficulties within the short term than spouses of women undergoing breast conserving surgery. However, these differences were resolved by 13 months (Omne-Pomten, Holmberg, Begstrom & Burns, 1993).

Sociocultural context.

As previously reviewed, body image and self-concept are dynamic constructs which are developed and changed both by private perceptions and social feedback. Social attitudes and cultural beliefs about body image and cancer can affect how patients view themselves, their illness, and future (Norris, 1978). To gain an in-depth understanding of breast cancer survivor's perception of their body image, it is important to explore and understand the sociocultural context that influenced the development of their personal body image.

The importance of body image throughout much of the western world, dominates much of our lives. Perhaps no other single aspect commands such a widespread expenditure of time, money, and effort as that of enhancing the appearance. From television and films to advertisements in magazines and on billboards, we are bombarded with pictures of the "ideal look". This image portrays a body free of any physical disabilities, perfect in complexion, hairstyle, and fashionable attire. One of societal stereotypes of women, equates a woman's looks with who she is. This assumption that self-worth is defined by the projected body image is internalized by many women and can profoundly affect how women react and adjust to alterations in their body as a result of illness and treatment (Seymour, 1998).

Numerous studies have documented the extent to which many women are tyrannized by arbitrary notions of beauty, which, in the second half of the twentieth century, have taken the form of skinny bodies with conspicuous breasts (Wolf, 1991). Female breast has become so idealized in our culture that it is the principal basis of a woman's identification with the female role. Breasts are not merely functional body parts, but rather are equated with femininity, sexual attractiveness and nurturing behavior. Women treated for breast cancer often face changes in their appearance including loss of their breast. In a society that places high value on breasts and physical attractiveness, these implicit messages can deeply effect women's experiences of their bodies after diagnosis of breast cancer (Kasper, 1994). The present study described women's perception and adjustment to changes in their body after treatment for breast cancer, and in the process explores the effects of societal and cultural attitudes on their personal perception.

Summary

The extensive existing research discussed thus far demonstrated that body image is a major concern for women who have been diagnosed and treated for breast cancer. How a woman views her body and incorporates this image into her self plays a key role in determining psychological adjustment and quality of life after treatment for this disease. The majority of existing research which examined the effects of breast cancer on body image is quantitative in nature and the measurements used lack the sensitivity to capture women's unique and individual perception of their body image changes resulting from the disease.

In the present study women are given the opportunity to describe their personal perception of the changes that have occurred to their bodies as a result of the different treatments for breast cancer. An holistic and comprehensive view is obtained from the women themselves to advance knowledge and in-depth understanding of their experiences.

CHAPTER THREE

INQUIRY

The Research Question

Audre Lorde (1980) in her book The cancer journals states that each woman responds to the crisis that breast cancer brings to her life in a personal way, which is the outcome of who she is and how her life has been lived. The purpose of the study was to explore, interpret and understand how women's body image was affected by the diagnosis and treatment for breast cancer. The study was guided by the following questions: How do women experience and perceive their altered bodies after being diagnosed and treated for breast cancer? How do women manage the threats to body image and identity and come to a resolution of the crisis in ways which preserve or redefine their understanding of themselves as women?

Approach to Inquiry

Qualitative research was chosen as the paradigm for this study because of the philosophical underpinnings that are fundamental to this research (Kvale, 1996; Moustakas, 1994; Patton, 1990; Van Manen, 1990). A qualitative inquiry emphasizes and builds on several interconnected themes (Patton). The world is not one made of constants but of multiple realities. The world is not objective, but is acknowledged as being socially created, emanating from personal interactions and perceptions. Perceptions are highly subjective and are composed of our beliefs and personal experiences. Thus, the researcher searches for *meanings and essences* of experience rather than measurements and explanations (Moustakas). The aim is to study real-world situations as they unfold in the *natural* environment, thus qualitative research has the natural setting as the direct source of data and the researcher is the key instrument. The *whole* phenomenon under study is understood as a complex system and it involves the researcher getting close to the data to obtain a rich description of the phenomena through interacting directly with the individuals who have experienced the phenomena. The researcher's personal experiences and insights are an important part of the inquiry and critical to understanding the phenomenon. Qualitative methods are particularly oriented toward exploration, discovery and *inductive* logic. An evaluation approach is inductive to the extant that the researcher attempts to make sense of the situation without imposing preexisting expectations on the phenomenon under study (Patton).

The following specific objectives guided the present study:

1. To collect descriptions of women's perceptions of their altered bodies after experiencing breast cancer.
2. To explore, analyze, and interpret these descriptions along with relevant data from research literature, to reveal the meanings and better understand their experiences.
3. To utilize these understandings as a basis for reflection upon existing perspectives on body image and breast cancer.

Within a qualitative research, the specific approach to inquiry which fits best with the objectives of this study, is the hermeneutic phenomenology approach.

Hermeneutic Phenomenology

Phenomenological inquiry focuses on the question: "What is the structure and essence of experience of this phenomenon for these people?" (Patton, 1990, p.61). The aim is to gain a deeper understanding of the nature or meaning of our everyday experiences. Kvale (1996) elaborates:

> Phenomenology is interested in elucidating both that which appears and the manner in which it appears. It studies the subjects' perspectives on their world; attempts to describe in detail the content and structure of the subjects' consciousness, to grasp the qualitative diversity of their experiences and to explicate their essential meanings (p.53).

Hermeneutics is a theoretical perspective that has increasingly informed and worked in conjunction with phenomenological inquiry in psychological research (Valle, King, & Halling, 1978). Hermeneutics is the study of the interpretation of texts. The aim is to arrive at an understanding of the meaning, with special attention paid to context and the original purpose (Patton, 1990). To make sense and interpret a text, it is important to know what the author wanted to communicate, to understand intended meanings, and to place documents in a historical and cultural context (Packer, 1985).

Hermeneutic phenomenology tries to be attentive to both terms of its methodology: it is a *descriptive* (phenomenological) methodology because it wants to be attentive to how things appear, it wants to let things speak for themselves. It is *interpretive* (hermeneutic) methodology because it claims that there are no such things as uninterpreted phenomena. The implied contradiction may be resolved if one acknowledges that the (phenomenological) “facts” of lived experience are always already meaningfully (hermeneutically) experienced. Moreover, even the “facts” of lived experience need to be captured in language (the human science text) and this is inevitably an interpretive process (Van Manen, 1990). In this interpretive inquiry the term phenomenology will refer to both descriptive and interpretive components.

Utilizing a phenomenological hermeneutic approach and using the lens of the feminist perspective which focuses on understanding the lives of women, I conducted a study which aimed at exploring and understanding women’s personal experiences and perception of their bodies after being treated for breast cancer.

Presuppositions

The construction of any work always bears the mark of the person who created it. In qualitative methodology, the investigator is the research instrument (Patton, 1990). Because qualitative work “closely involves the researcher with participants and data…questions about how personal experiences, perceptions, and interpretations enter into the data are of particular interest” (Daly, 1992, p.9). As such, the researcher’s subjective experiences of data gathering and analysis must be made as explicit as possible. What is required of the researcher is to try and become conscious of one’s own presuppositions and modes of influence and lay out his or her assumptions through conscientious self-reflection, known as bracketing (Osborne, 1990). Reflection on the influence of personal experiences and insights create not only personal awareness of how the researcher is shaped by one's own biography, but also provides a context within which audiences can more fully understand the researcher's interpretation of text data. The following is a description of the development of my interests and values as they framed the process of inquiry in this study.

The choices that I have made regarding the question of this study and the manner in which it was explored was reflective of my clinical experience as a psychologist and the theoretical knowledge I inquired on this subject. The interest to conduct a study on women and breast cancer was instigated by my clinical experience as a psychologist working in the area of psycho-oncology. Over the past nine years I worked in a regional cancer hospital, providing therapy for cancer patients and their families. A major part of my work involved counselling women with breast cancer. In individual and group sessions women shared their experiences with a life threatening disease, which caused havoc in their life and shook its foundation. I was deeply affected by their shared experiences, and their courageous fight to survive and recover. I also became aware how body image issues were intertwined in all of the breast cancer stories. As I turned to the literature to explore the present knowledge available on body image and breast cancer, I became aware of the paucity of information that addressed body image from the perspective of the women who experienced it. It became the focus of my interest to explore and gain in depth understanding of women's personal perspective of their changed bodies after treatment for breast cancer. Researching within a qualitative approach allowed me to remain close to the experience of the participants in a similar manner as counselling allowed me to intimately view a client's world. My professional experience as a psychologist helped me to maintain boundaries and keep my subjective views in-check.

My personal values, beliefs, and assumptions influenced my approach and interpretations of this study. Influenced by feminist approaches, I believe that one of societal stereotypes of women, equates a woman looks with who she is. This assumption that self-worth is defined by the projected body is internalized by many women. Furthermore, female breast has become so idealized in our culture that it is the principal basis of a woman's identification with the female role. In a society that places high value on breasts and physical attractiveness, these implicit messages can deeply effect women's perceptions and adjustment to changes in their body images after undergoing treatment for breast cancer. When listening and reflecting on participants stories, I was aware of these personal beliefs and their potential influence on the study interpretations.

Research Participants

Eight women who were diagnosed and treated for breast cancer participated in this study. Selection of participants proceeded via a purposive sampling procedure advocated by qualitative inquiry (Morse, 1995; Patton, 1990). In purposeful sampling, subjects are selected because they have experience with the phenomenon being studied, are able to express themselves and are willing to share their experiences with the researcher (Morse, 1995). Selecting a size for the sample in qualitative research has less to do with the number of participants and more to do with purposefully involving participants who could provide in depth and rich descriptions around the phenomena being explored (Patton, 1990). The number of participants is ultimately determined by the quality of the information that emerges through the inquiry process. In qualitative research, the investigator samples until repetition from multiple sources is obtained. This provides concurring and confirming data, and ensures saturation (Morse, 1995).

The eight women who participated in the study were diagnosed and treated for breast cancer and were willing and able to share their experiences with the researcher. They provided in depth information of how the experience with breast cancer affected their perception of their body image. Interviews were conducted until a redundancy of themes was heard. Gathering of data was stopped when it was felt that diversity had been achieved and a solid data base established.

Participants in this study had the following selection criteria: all experienced breast cancer; were premenopausal (under the age of 50) at the time of diagnosis; free of recurrence with no evidence of metastatic disease; finished treatment for at least one year (except tamoxifen in hormone receptor positive disease); had different treatment modalities; willing to discuss their experience with the researcher; able to articulate their experience; able to speak and understand English fluently.

The eligibility criteria were established on findings reported by previous research on breast cancer. Research conducted on body image and women with breast cancer revealed that breast cancer patients manifest age-related differences in the psychosocial impact of their illness (Mor, Malin, & Allen, 1994; Northhouse, 1994; Rowland & Massie, 1998; Siegel, Gluhoski, & Gorey, 1999; Vinokur, 1990). Younger breast cancer patients reported high levels of emotional distress regarding their bodily changes, which is related to specific issues associated with their developmental age (Mor et al., 1994; Siegel et al., 1999). As well, younger women with breast cancer were treated with chemotherapy much more frequently than older women. This is because the cancer, when found in younger women, was more likely to be aggressive and recur. Consequently, they were more likely to endure the possible side-effects caused by this treatment (Schover, 1994). Socially accepted definitions of age appear to vary substantially from decade to decade, and between social and ethnic groups. Mor et al. suggested that menopause represents a convenient way to cut the age distribution. Thus, this study focused on women who were premenopausal at time of diagnosis (under age 50).

Research conducted with women treated for breast cancer suggested that investigations of body image may not yield valid results if they were conducted immediately after surgery (Glanz & Lerman, 1992, Penman et al., 1987, Polivy, 1977; Taylor, 1985). As well, participants who were going through the experience of treatment, may not have the time or the energy to make sense of the experience, therefore it was recommended that participants be chosen from among those who have passed through the experience (Morse, 1995). The criteria for no metastatic disease reflected the assumption that in advanced stage of the disease women may be focused on treatment and survival issues which can become their major source of concern.

To promote maximum variation of data, participants had different treatment modalities and different marital status. With the emphasis on interviewing as a means to collect data, potential participants needed to be willing to describe their experiences and have the ability to articulate their experiences clearly.

Access to the participants was facilitated through a group of family physicians, through referral from other participants, and through a psychologist in private practice. The researcher gave an information sheet (see Appendix C) to the physicians, the psychologist, and the participants who spoke to other breast cancer survivors who expressed interest in participating in the study. The information sheet included the study description, eligibility criteria, the researcher's name and telephone number and a permission to release their name and telephone number to the researcher. All women were initially contacted by the researcher. Four women were referred by the physicians, three by other participants and one by the psychologist.

The eight women who participated in the study ranged in age from 36 to 46. The average age of the participants was 43. Six of the women were married and two were separated. With respect to their education, six women had a high-school diploma, one woman completed an undergraduate university degree and one woman was studying for her graduate degree. All women were working outside their home: four were employed full time and four held part-time positions. All the participants had children and their ages ranged from 4 to 24 years old.

The time since diagnosis ranged from 2 to 5 years. Participants received varied types of treatments. All the women underwent surgery, with six women receiving mastectomies and two receiving lumpectomies. Two women chose to also have breast reconstruction surgery. One woman had a TRAM flap reconstruction and one had saline implant. All women received additional treatment after the surgery: chemotherapy and/or radiation, and/or hormonal therapy. Seven women received chemotherapy after their surgery, five women received radiation treatment and three continue to take hormonal treatment. Three women received all three treatments: chemotherapy, radiation and hormonal therapy. Five women received chemotherapy and radiation.

Acquiring the Data

Data were collected through in depth interviews, research journal and demographic questionnaires. In depth interviews were used as the prime source of collecting data. The main purpose of the research interview was to "obtain descriptions of the life world of the interviewee with respect to interpreting the meaning of the described phenomena" (Kvale, 1996, p. 5). The research interview is a specific form of conversation, that has a structure and a purpose. As Kvale points out, in an interview inquiry a substantial familiarity with the theme and context of the inquiry is a precondition for the use of the interview method.

The interview form utilized in this research was the semi structured interview: It has a sequence of themes to be covered, as well as suggested questions. Yet, at the same time, there is an openness to changes of sequence and forms of questions in order to follow up the answers given and the stories told by the participants (Kvale, 1996; Patton, 1990). Patton described the general interview guide approach to collect qualitative data from interviews. This approach involves outlining a set of issues that are to be explored with each participant before the interviewing begins. However, these issues do not need to be taken in any particular order, and the wording of questions is not specifically determined in advance. The interview guide serves as a "checklist", to make sure that all the relevant topics are covered, and there is some common information that the researcher wishes to obtain from each participant. The interview guide assisted me in pursuing topics of interest pertaining to the research question (see Appendix D). Questions for the present interview guide were derived from the literature on body image and breast cancer, as well as information gathered through my clinical experience while working with women who had breast cancer. The questions were modified in response to the participants' comments and probing was often used to elicit clarifications or further elaboration.

Kvale (1996) stated that "the outcome of the interview depends on the knowledge, sensitivity, and empathy of the interviewer" (p.105). In a research setting, the interviewer must establish in a short time an atmosphere in which the participant feels safe enough to talk freely about his or her experiences and feelings. It is the sensitivity and emphatic understanding that allows people to share their thoughts and emotions most fully (Osborne, 1990). In commencing each interview I took time to establish rapport by sharing with the participants my clinical experience working with women with breast cancer. When exploring body image issues with women participants I was involved in an interactive process, and entered into a "complementary relationship" (Guba & Lincoln, 1981, p. 193) with the women. Essential to this relationship is not the objectivity of a quantitative researcher, but rather sensitivity and emphatic understanding. The way in which I presented myself to the participants likely contributed to my success in gaining entry and engaging them in the research process. As one participant remarked: "I feel that you understand where I come from, and I could tell you things that were very much inside me and I didn't share before" (a participant).

At the end of each interview, all of the participants commented that participating in the study was very beneficial. Hutchinson, Wilson and Wilson (1994) described how people benefit from being involved in in-depth interviews. These benefits include: (1) catharsis, (2) self-acknowledgment, (3) sense of purpose, (4) empowerment, (5) self-awareness, (6) healing, (7) providing a voice for the disenfranchised. The women in the study expressed similar benefits and commented on the potential benefits to other women.

I kept a research journal in which nonverbal observations were recorded after each interview and were used to supplement the data obtained in the taped interview. Notes were made concerning areas which might be explored in more depth during interviews with other participants. My own reflections, ideas and conjectures were also recorded during the lengthy analyzing, reading and writing process. The demographic questionnaire was completed at the beginning of each interview and served as a third source of data (see Appendix B). It included information on the participant's age, level of education, marital status, length of marriage, number of children, occupation, date of diagnosis, brief treatment history, and stage of the disease. This information was used to describe the participants.

Interview Procedures

Each participant was interviewed twice: the first interview was held face-to-face and the second was a telephone conversation to validate the interpretations of the results. The first interviews were conducted during the months of October, November, and December, 1998. Each interview lasted approximately one and a half to two hours. Six interviews were held in the researcher's office, one interview was held in the participant's home, and one interview in the participant's office at her work site.

Women, who met the study criteria and expressed interest in participating in the study, gave permission to be contacted. The researcher contacted each participant and provided information about the purpose of the research and the time commitment required for the study. A place of meeting was mutually decided. In commencing each interview, I took time to explain again the nature of the study and further details were provided. To establish rapport and a sense of trust I included information about my professional experience working with women who were diagnosed with breast cancer and the profound effect it had on my personal life. Informed consent, confidentiality, and participants' rights to withdraw from the study were discussed. The participants were assured that the results would be mailed to them and a telephone conversation would follow to discuss their comments. After obtaining the demographic data, I invited the participant to share with me their perception of their body image after being treated for breast cancer.

After the analysis of the transcripts was completed, a summary of the themes was mailed to the participants. A telephone conversation followed to inquire whether the analysis fit with their experience and whether they had additional comments or thoughts. All the participants agreed with the general themes. Some added comments and offered further information on some topics.

Analysis of the Data

The data for the present inquiry consisted of eight transcribed interviews, my journal reflections and demographic information. The journal reflection contained my observations and impressions documented at the time of the interviews. The demographic data included the information provided by each woman at the beginning of each interview.

Shortly after completing each interview, I personally transcribed it verbatim. When I first listened to the interview audio tapes, I wondered whether I could do justice to women's narratives in my analysis. I did not want to give an incomplete, or inaccurate account of the meanings of participants' experiences in my interpretations of their voices to others. Denzin (1994) calls the complex, reflexive process of moving from the field to the text, to the reader the "art of interpretations". Patton (1990) states that there is typically not a precise point at which data collection ends and analysis begins. In the course of gathering data, ideas about possible analysis occur. Those ideas constitute the beginning of analysis and they are part of the journal reflections. They serve as indication and direction for further probing and explorations. This overlapping of data collection and analysis improves both the quality of the data collected and the quality of the analysis (Patton). I was aware that some of my interpretive thoughts that would shape the creation of a textual work had originated during the interviews when I began to formulate ideas about the analysis. Yet, it was not until the transcribed texts were before me that I was able to fully engage in the challenge of data analysis.

Miller and Crabtree (1989) suggested that all qualitative analysis must address three basic steps: "developing an organizing system, segmenting the data, and making connections (p. 395). However, it is Van Manen (1990) who points out that "too often theme analysis is understood as an unambiguous and fairly mechanical application of some frequency count or coding of selected terms in transcripts or texts" (p.78). He further suggested that:

> Making something of a text or a lived experience by interpreting its meaning is more accurately a process of insightful invention, discovery or disclosure- grasping and formulating a thematic understanding is not rule-bound process but a free act of "seeing" meaning (p.79).

Themes in hermeneutic phenomenology are simplifications, or attempts at organizing, capturing, and structuring experience. By identifying themes, the researcher is striving to better understand, or make sense of the experiential material. Themes are generally uncovered from text by examining the text as a whole, by selecting specific or essential phrases, or by examining the text line by line. Once themes are identified, they then become objects for further reflection by the researcher (Van Manen, 1990).

Based on Colaizzi (1978) and Van Manen's (1990) approach, analysis and interpretation began with the phenomenological reduction of the data and evolved into the hermeneutic crafting of a text. Following Colaizzi's first step, I listened to the audio tapes while reading the transcripts, in an attempt to acquire "a feel" for the experiences of each of the participants. Next, I approached each protocol and highlighted phrases or sentences which expressed meaningful themes. "Formulating meanings" (Colaizzi, 1978, p.78) from the extracted sentences was accomplished through transforming the phrases as they appear in the transcript into my own words. This allows the theme to move beyond the participants statements and illuminate the essential meaning of the phenomenon described. This procedure of extracting significant statements and creating themes was repeated for each of the eight women.

The next phase included organizing the completed formulated meanings of each individual protocol into clusters of themes. Once individual themes were identified, I began comparing the themes among the eight women, looking for confirmation and discrepancy. After weeks of being immersed in the text, thinking, rethinking and returning to the data, a variety of themes emerged and became the basis for a creative synthesis of the data, which then led to the writing of chapters four and five.

As noted by Daly (1992), the challenge for the researcher is to preserve participants' meanings while being aware of personal and professional meanings that permeate analysis. I was aware that my professional background and familiarity with the literature and, to a lesser extent, my personal experiences, were influences on my interpretation of the data. They were bracketed in the section that addresses my presuppositions in the study. However, I believe they not only gave me "a priori" familiarity with relevant issues but also enhanced my ability to make sense of the data.

To verify the findings and the interpretations, I provided a brief summary of the resulting themes for each of the participants. This presentation was necessary to verify, or validate how the results of the analysis compared with the experiences of the participants. The feedback provided by the participants indicated that the themes reflected their experiences and meanings.

Trustworthiness

Whatever the specific techniques of inquiry and presentation, human science research must be trustworthy, a quality achieved by maintaining a sense of rigor throughout the research (Patton, 1990; Sandelowski, 1986). Rigor refers to the process of planning and conducting the research and analysis, while trustworthiness is applied to the data, the findings, and the conclusions reached by the researcher. To have trustworthiness in the findings, there must be rigor in how the research has been done. Sandelowski (1993) stressed that there is inflexibility, uncompromising harshness, and rigidity implied in the term rigor, which takes us too far from the "artfulness, versatility and sensitivity to meaning and context, that mark qualitative works of distinction" (p.1). Rigor is therefore less about adherence to the letter of rules and procedures than it is about fidelity to the spirit of qualitative work (Van Manen, 1990).

Lincoln and Guba's (1987) criteria for trustworthiness were used as a primary framework for establishing the trustworthiness of this study. These authors viewed the researcher as the primary instrument and as such need to convince the reader that the findings are trustworthy by ensuring credibility, transferability, dependability, and confirmability.

Credibility

In contrast to quantitative research, where researchers use tools and instruments for inquiry, the researcher in qualitative research is the primary instrument. Hence, the credibility of this inquiry relies first and foremost on my own abilities and qualifications. Miles and Huberman (1984) identified four criteria for assessing the credibility of the researcher: (1) familiarity with the phenomenon and the setting under study; (2) a strong interest in conceptual or theoretical knowledge; (3) the ability to take multidisciplinary approach; and (4) good investigative skills, which are developed through literature review, course work, and experience in qualitative research methods. My educational preparation, research experience, and clinical experience as a psychologist working in a psycho-oncology setting suggest that these criteria have been met.

Lincoln and Guba (1985) asserted that credibility occurs when the results present a faithful description and account of the participants' experience of the phenomenon. To increase the probability that credible findings would be produced, I asked each of the participants to review the thematic analysis and comment on the accuracy of the analysis with their own experiences. This validation and clarification of data, interpretations, and conclusions was conducted during the interview process and at the conclusion of the study. Another method of enhancing credibility in qualitative study is by continually returning to the data, texts, or expressions generated by the participants. Throughout the research, I remained in close contact with the data provided by the women, continually checking, questioning, and theoretically interpreting the findings.

Transferability

Transferability is the criterion used to determine whether the findings can be applied in other contexts or settings or with other groups. In a qualitative research, it is acknowledged that since only a small number of people are interviewed, the findings are relevant to the time and context of the particular study. Sandelowski (1986) noted that "every research situation is ultimately about a particular researcher in interaction with a particular subject in a particular context" (p. 31). She further stated that stories that people tell in interviews are themselves constantly changing, since they represent their efforts to order, find meaning in, and even live with the events in their lives (Sandelowski, 1993).

Lincoln and Guda (1985) noted that it is not the task of the qualitative researcher to point to the transferability but " provide only the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether a transfer can be contemplated as a possibility" (p.316). A purposeful sample technique was used to select participants to ensure that they possessed the characteristics needed for the study, and would articulate their experiences. This sampling procedure allowed for in-depth descriptions which would enable others to consider transferring the findings.

Dependability

The criterion of dependability is auditability which is evident when the decision making trail followed by the researcher throughout the study is clearly documented for the reader, allowing the reader to review the reasoning process (Guba & Lincoln, 1981; Sandelowski, 1986). To enhance auditability, an audit trail was developed which documented all research choices, decisions, and insights. Field notes were completed after each interview, outlining my observations, questions and emerging ideas. Also, recording my subjective interpretations and impressions assisted me in being alert to areas of potential bias.

Confirmability

Confirmability is the criterion of neutrality, or the extent to which the results reflect the experiences of participants, free from the biases of the researcher. An important component of validity in qualitative research rests on the researcher's self-reflection, monitoring, and recording preconceptions and biases throughout the research process (Morse, 1995). Reflection on the influence of personal experiences and insights create not only personal awareness of how the researcher is shaped by one's own biography, but also provides a context within which audiences can more fully understand the researcher's interpretation of text data. During this inquiry, confirmability was enhanced through my recording of my clinical experience in the area of psycho-oncology, as well as journalling subjective impressions and observations throughout the research process.

Ethical Considerations

An interview inquiry is a moral enterprise as the personal interaction in the interview affects the participants and the concern for their well being is paramount (Kvale, 1996). Ethical issues that may arise at different stages of the inquiry include: informed consent, confidentiality, and consequences.

Prior to conducting this inquiry, I obtained approval from the University of Alberta Research and Ethics Committee in the Department of Education Psychology. When I met with each participant, I explained the nature of the study and a written consent was obtained prior to beginning of the interview (see Appendix A). Two copies of the consent form were signed: one copy was given to the participant and one was retained for my own records. Participants were not coerced or pressured in any way to participate in the study. They were assured they could freely choose not to participate, withdraw at any time, refuse to answer any questions, and request that any information not be included in the research reports. All the participants were provided with my telephone number so they could have questions or concerns addressed at any time.

Confidentiality was maintained throughout the research process. Pseudonyms were used on the written material. Any identifying statements or references have been removed. In this research report, care was taken to conceal identities by providing a general description of the entire group of participants rather than individual descriptions that might reveal their identities.

Due to the sensitive nature of the topic of this study, it was possible that participants might become upset or distressed by the discussion of their illness. As a psychologist with extensive clinical experience, I was sensitive to any indication of distress by the participants and was ready to offer support when necessary. If needed, I was prepared to provide the participants with a counselling referral, but no such need arose.

Chapter four presents the themes that emerged from the analysis of the interviews. They are described and illustrated with quotations from the women participants. These themes depict the participants perception of their changed body image after treatment for breast cancer.

CHAPTER FOUR

FINDINGS

How did the experience of breast cancer affect your body image? This initial, opening question, prompted eight personal stories. In this chapter, a brief description of the participants is presented. Following this description, the themes that emerged from the analysis of the interviews are described.

Liz is a 43 year old married woman who has two children ages 14 and 16. She was diagnosed in May 1997 and underwent mastectomy followed by chemotherapy. After completing the treatment for breast cancer, she decided to return to school and pursue her "big dream" of a graduate degree in the health sciences. She is presently a full-time student.

Julia is a 43 year old woman. She has been married for 20 years and has a daughter age 10. She has a university degree and works part-time with her husband in a legal field. She was diagnosed in December 1996 and underwent mastectomy, chemotherapy, as well as radiation therapy.

Mary is a 41 year old woman. She is separated from her husband and has one daughter age 5. They presently live with Mary's mother. Mary completed grade 12 education and works full-time in broadcasting sales. She was diagnosed in August 1997 and underwent mastectomy and chemotherapy. She is presently undergoing a breast reconstruction procedure.

Jennifer is a 45 year old married woman who has two children ages 12 and 4.5. She completed grade 12 education and is self-employed. She was diagnosed in April

1997 and underwent lumpectomy followed by chemotherapy and radiation. She continues to take the hormonal therapy Tamoxifene.

Karen is a 36 year old woman and has three children ages 11, 13, and 15. She is presently separated from her husband. She completed grade 11 education and is working full-time in sales. She was diagnosed in march 1997 and underwent lumpectomy and radiotherapy.

Holy is a 38 year old married woman. She has two children ages 10 and 11. She completed grade 12 education and works full-time in an administrative position in a large company. She was diagnosed in August 1996 and underwent mastectomy and chemotherapy. She also went through breast reconstruction surgery.

Leah is a 45 year old woman. She has two adult children from a previous marriage who do not live at home. Her three younger children, ages 15, 8, and 7 live at home. She works part-time in sales. Leah was diagnosed in December 1996 and underwent mastectomy, chemotherapy and radiation.

Rose is a 46 years old married woman who has no children. She works full-time in the school system. She was diagnosed in February 1992 and underwent mastectomy, chemotherapy and radiation. She continues to take the hormonal therapy Tamoxifene.

Overview of the presented themes

There were seven themes that emerged from the analysis of the interviews. These thematic clusters are interrelated, and often overlapping. There is an interplay between and among the themes and this overlap and interaction is consistent with the complexity of human experience. This will be especially evident in themes related to appearance, femininity and sexuality. Issues concerning gender must inevitably engage with sexual themes. I raise this in order to prepare the reader for some repetition of data associated with the interconnected themes in the study.

The emerging themes are described and illustrated with quotations from the women participants. These themes are unlikely to be exhaustive categories of body image. Inevitably, these are selective conceptual or thematic simplifications of my understanding of the way women perceive their bodies after treatment for breast cancer. My intention here is to elucidate new meanings and thereby to broaden our understanding of what it is like to experience changes in body image after breast cancer. Van Manen (1990) points out that the insights and descriptions gained from a piece of phenomenological work are only one interpretation of a description. Another researcher may uncover different meaning structures. It is my hope that from this presentation, one will be able to see how I moved from participants' own words to the final description of the experience.

While interviewing the eight participants, it became apparent that each woman brought to the interview her own unique background and personality which made her perception of her body solely her own. However, there do appear to be common and similar experiences that all the women shared after being diagnosed and treated for breast cancer. There were seven main themes that emerged from the analysis of the interviews, and each of the themes had several sub themes or related issues. The themes are:

1. Body image, a personal perspective

  - "I want to look trim, slim, muscular, and strong"
  - "Body image relates to my sexuality"
  - "Body image is how I look in the mirror and how I look to others"
  - "Body image is how I feel about myself inside"

2. The objectified body
   - The body as an object
   - The voice of medicine
   - The body in pain
3. The functional body
4. The visible and observed body
   - Changes in appearance
   - Concealing the changes
   - The glance of others
   - The naked body in the mirror
5. The feminine body
6. The intimate body
   - The same, but different
   - The hidden body
   - Being sexually intimate
7. Integrating body image into the self
   - Grieving the losses
   - Creating changes

Body Image - A Personal Perspective

Intertwined in the breast cancer stories were women's reflections about their personal histories that shaped and influenced their perception of their body image. These stories aid in understanding the participants' responses to the changes that have occurred to their bodies after breast cancer.

"I want to look trim, slim, muscular, and strong"

Liz's body image was closely related to her sport activities and her strong identity as an athletic woman: "I want to be trim, slim, muscular, and strong...For me, if I was super athletic, and my body was toned and fit, I would feel and look sexy, and would come across as a beautiful woman". She was brought up in a family of five brothers and two sisters. She described herself as being "a large girl. By grade 6 it was obvious that I couldn't wear my sister's clothes any more, although she was nine years older than me". Liz was also the largest girl in her class, and "my whole image of myself in relation to the other girls was that I was big". She recalled:

> When I was in my late teens, or early twenty I exercised a lot: I row competitively, cross country ski, swim, and I was really athletic. I was really lean and still thought that I was fat because I couldn't get into my head that I had big hands and feet and shoulders, just an image of being a huge person.

She remembered an aunt telling her mother: "She is so big, she should try and loose weight. And this kept on through my youth that I was big". Her mother "is compulsive about weight, she is forever on and off different diets, and she uses diuretics, anything to loose weight...So my family is obsessed about being fat and body image for us is weight control". This was Liz's understanding why gaining weight during chemotherapy was so devastating for her.

"My body image relates to my sexuality"

Karen felt that her body image was closely related to her sexuality. As an attractive woman she was fully aware of her good looks. She described:

> When I grew up my good looks were the focus of the attention I got and I ended up putting a lot of emphasis on it. I always noticed men gazing at me and may be that's why I learned to connect my body image with sexuality. I have a tendency to rely too much on my attractiveness and I made it a high value for myself to keep my appearance. I sometimes think it's a weakness in my character but that's the way I felt.

Karen received similar messages from her husband and when diagnosed with breast cancer she was prepared "to risk my health to conserve the breast and the nipple".

"Body image is how I look in the mirror and how I look to others"

Holly and Jennifer admitted to place high value on their appearance. For Holly, "Body image is how I look in the mirror, and how I look to others…It was always very important for me how other people see me". She recalled messages from her parents referring specifically to her weight. She was also greatly influenced by the media and the different advertisements which promote unrealistic expectations on women's body. Holly's body image was deeply affected by the breast cancer. She was devastated by the changes to her body and experienced depression and profound sadness. She decided to have breast reconstruction which helped to restore her body image.

Hair was associated for Liz with a sense of femininity. She described:

> When I grew up I looked like a boy and people mistook me for a boy. I had a deep voice and I looked like my brothers and my mom cut my hair short, pixy cut, so I got used to thinking that if I had short hair I would look like a boy and therefore kept my hair long. I did have beautiful, waist-long, thick reddish hair, and it was part of my self image.

When she lost her hair as a side effect of the treatment, her body image and sense of femininity were deeply affected. The loss of the breast was less traumatic as "I was pretty flat and the standard joke was that I had no breasts".

"Body image is how I feel about myself inside"

Mary, Leah and Rose viewed their body image as an inner reflection on how they felt about themselves and their personal self worth. Mary felt that overall she was always pretty satisfied with the way she looked. She stated:

> In general I don't have an issue with the way I look. Barbies contributed to the unreal view of body image when I grew up. But my perspective has always been pretty realistic. I never wanted to look like a woman in a magazine. They are a small fraction of the population and it doesn't make the big majority look ugly. Normal, average, is beautiful in my opinion. If you are born a certain way you need to accept it. That's the way I was brought up. Wishing for something else doesn't help, so you accept the way you are.

After being diagnosed with breast cancer, she underwent surgery followed by chemotherapy and radiation and she stated that "the physical part of my body changed but not the way I feel about it. I don't like myself now more or less than before". She decided to have reconstruction "for convenience reasons", but without expectations that the operation will "bring back my old breast".

Leah related body image to: "how I feel about myself. To me body image is the whole person, how I look, but mainly what's going inside the person is more important".

She elaborated:

> Growing up it had to do with how you fit into your group, what's your weight, and I was very much part of that at the time. But I got over that very quickly...When I was 20 I did modeling. That could have been the time that started the change in my body image because you get treated like a piece of meat, so I learnt very quickly that nobody is perfect, but they artificially try and make you look perfect...So for me it was all phony. That's an unrealistic idea but not the way even the models look like. I realized it was all a show that dictates women's expectations. I started to understand, even then, that how I feel inside is what really counts.

The participants' perception of their changed bodies can be better understood when viewed in relation to their life stories and their past experiences with body image. Although their experience with breast cancer was unique, commonalties and shared experiences did emerge along their path to recovery. The following are themes that emerged from women's stories about the effects that the cancer experience had on their body image.

The Objectified Body

The Body as an Object

Cancer is powerfully equated with death, and in the fight to survive, the women of this study encountered a personal crisis that created a separation between the body and the self. The body was treated as a conglomerate of fixable or replaceable parts, and the breast was considered detachable, dispensable. At the time of diagnosis, the issue of losing a breast was subordinate to issues of health and survival. Each woman described a profound fear of death when first confronted with the diagnosis of cancer. The major decision of surgery was viewed by the women almost as a non decision. They spent little time deliberating the benefits and risks involved in the surgery. The only alternative they attended to was one that offered them hope of cure. As Julia recalled:

> The mastectomy was not a choice. I had two lumps and a mastectomy needed to be done, so I didn't have it researched or analyzed. It was the only way of dealing with it.

Seven women were raising young families which intensified their fear of death. The breast became a body part associated with danger and a risk to their life, and as such needed to be separated and, if needed, removed. Leah's initial response to the diagnosis was similar to all other participants. She stated:

> The focus was if I am going to live, where has it gone to, am I going to be alive and raise my family. If the breast had to come off, it will come off.

For Jennifer, a mastectomy meant that she will be cancer free, allowing her an increased sense of security at a time filled with uncertainties. She recalled being apprehensive when she discovered that her surgeon had performed a lumpectomy instead. She stated:

> In the hospital I said to my surgeon: I want you to remove my beast to make sure that the cancer is gone. So I was upset when I came out of surgery and found out that he did a lumpectomy. Since than I talked to my doctors several times if I was not better off with a mastectomy.

In the fight to survive, the diseased breast became a body part, an object to be conserved or lost, but always secondary to survival. As a separate body part, the objectified breast was not signified with femininity or sexuality, which are part of the self, and was often referred to as *it*. As most women stated: " if *it* has to come off, *it* will come off, and that's a priority."

Holly reflected on her reaction at the time of diagnosis to loosing her breast and commented on the sudden, abrupt change in her attitude towards her breasts:

> I always liked my breasts. They were nice, and they were my best feature…But when I was diagnosed with cancer, all of a sudden I said, a breast is just a breast, cut it off and it's not such a big deal.

Mary, who had undergone a mastectomy, characterized her breast as a limb, contrasting it to arms and legs. Viewing the breast as a limb, de-emphasized the uniqueness of breast cancer in distinction from other cancers. She stated:

> If I had to loose a limb, that's the one that I'd loose. A missing breast doesn't incapacitate you. Having a wooden leg is far worse because it restricts your mobility.

Liz expressed similar thoughts: "After all, it's not like having your liver removed, or having a colostomy. It's just a breast".

After mastectomy some women referred to the area of the lost breast as "my chest", or "chest wall" devoid of sexual meaning. Liz recalled:

> After the surgery my son wanted to see what the scar looked like, and I said: You know, I don't have a problem with you looking at it, but I'm covering the other breast because it's private.

The objectified breasts were constructed as physical body parts with disease but without addressing the emotional issues in the context of women's bodies and lives.

The Voice of Medicine

The language of medicine reduced each woman to a patient with a specific diseased body part which is separated from the whole of women's bodies and the texture of their lives. The often highly abstracted medical language, with its talk of stages of disease and treatment plan, objectified the body and gave little insight into deep and significant feelings that breast cancer evoked.

Women's breast cancer stories began by describing their personal illness histories. All the participants, to varying degrees, used clinical and technical language to describe their experiences. This language especially pervaded the beginning of the interviews, where the breast cancer experiences were cast in terms of diagnosis and treatments: mammograms and biopsies of tumors "2.00 centimeters" and "stage II"; lumpectomies, mastectomies; lymph nodes involvement and "clean margins"; estrogen-receptor-negative or positive; radiation therapy, chemotherapy and tamoxifen; and a TRAM procedure. Women repeated language from medical consultations and researched their own diseases, learning a new vocabulary. One woman remarked that she could "practice medicine" after all the reading she has done.

From the point of view of medical practice, the body was an object, a substance upon which medical practices were performed. The body under the medical gaze was a thing, an object, devoid of personal identity and separated from the self. Karen, while going through treatment, talked about "people who were doing things to my body but paying no attention to my self". In self-protection, she separated her "self" from her "body" and used the metaphor of a "body as a house". She described:

> When I went through radiation, I felt so exposed, men and women walked around me, drew lines on my body, touching me here and touching me there, and after every test I made myself think that the body just houses us. The body is just a house we live in, and it's been treated, but not the actual person inside. So it's not that important if all these strange people see my body and touch me.

Rose felt "exposed, like on a stage, with the audience free to question, examine, inject, and cut". She further described:

> Before radiation started I had to be measured. I lay there, naked, while the technician was marking around my breast with a pencil. I felt so vulnerable, so exposed. I kept saying, it's not happening to me, I'm not here.

Other women also talked about their body under treatment as separate from the self, and women recalled "feeling numb" and "detached".

The Body in Pain

Diagnosis and treatment of breast cancer resulted in a traumatized body, subjected not only to the fragmenting and objectifying language of medicine and the dread of cancer, but also to the violence of treatments. The interviews contained numerous descriptions of the body in pain as direct surgical and treatment effects. Instances of severe bruising and swelling were described: "it was so very red and sore", "it was blistered and painful", "it looked and felt like a very bad burn", "it was itchy and irritating". Where as before, breasts were taken for granted, with surgical and radiation treatments, they were now stark sources of physical pain.

Women described their treatments in a war like language, and battle analogies were often used. Injunctions like: "slash, burn, poison", "barbaric", " mutilation", surgery as "an assault on the body", and radiation as "an invasion of the body" were used in their descriptions. This language reflected an approach to a war that must be fought, not against an outside force, but against the women's own bodies. An assault on the body had occurred until such time as a reintegration of the self and the body concept was achieved.

The Functional Body

A woman's perception and appraisal of how her body functions is an integral part of her body image. In this thematic cluster, the body was described by the women in relation to its function, that is, what biological and characteristic activities it enabled women to perform. Meanings for the functional body placed less value on the visual body (described in the third theme), how it looks, and more value on what the body, and particularly the breasts, "do" for women.

Treatment related problems, such as physical limitations from surgery, pain, and fatigue disrupted women's home life and work and interfered in their functioning.

As Rose stated: "My body just couldn't do what it used to in the past". Holly described it as "being out of circulation", and Leah's body "stopped functioning".

For most women, the functional repercussions of breast cancer were measured by its impact on their daily ability to be active, and on the body's movement. "Lopsidedness" following mastectomy resulted in limitations to physical activities. Women talked about uneven weight distribution, of the remaining breast pulling on one side. Rose, who liked riding horses, commented: "when I ride my horse, my body is out of balance and not in-tune with the movements". Liz who was engaged in many sport activities like running, rowing, cross-country skiing, and swimming, commented on how having one breast interfered with her running. She also gained a great deal of weight as a result of the chemotherapy. She used the prosthesis, which to some extent, improved the sense of balance, but she remarked that the affect it had on her sport activities was profound. In an attempt to incorporate the loss of the breast into her new reality, she tried to rationalize having only one breast as a "kind of an asset". She stated:

> I read about women who chose to have one breast removed because they were archers, so they can pull the bow back easier. I used to do archery and I thought, great, I can do it too. Now I do a lot of rowing and I thought it can help me in my rowing.

The prospect of lymphedema was troublesome for Rose who felt that she had to protect herself against such minor injuries as insect bites, paper cuts, and burns. She was unable to lift heavy weight with this arm which restricted her activities. Holly who underwent a "tummy tuck" as part of the breast reconstruction, described problems associated with the loss of stomach muscles and restricted mobility.

This theme reflected women's perceptions of the effects the treatment for breast cancer had on the functioning of their body. It also challenged the reduction of breasts to their mere appearance. Although this cluster contained fewer statements than other clusters, it reflected women's concerns about their bodies ability to function and be active.

The Visible and Observed Body

Physical appearance is a conspicuous aspect of the self. The external body presents itself boldly to the world and it is subjected to the view and appraisal of others. Breast cancer treatments brought increased body-consciousness to all participants, regardless of type of treatment. The changes in their body became the focus of others' attention. The visible body was not only observed by others, but was also self-observed privately by each woman, and their self-image was reflected in the mirror. The two perspectives are inter-related but separate.

Changes in Appearance

Body image is closely related to a sense of wholeness, matching and balance. When a breast is removed the body becomes asymmetrical. When Liz was first told about the need to have a mastectomy, she knew that her breast would be removed, but she had no idea what it will look like. She recalled:

I had this idea that they take all the tissue out, but the nipple is left, and when a

> nurse friend told me that they take the whole thing, than it dawned on me what's it going to look like and I was terrified…I thought it will look like nothing, like out of proportion, and artistically it will look goofy, why will I have a dot for a nipple on one side and nothing on the other?

She continued :

> We think of ourselves in symmetry. When the face or the body is not symmetrical it is noticeable. Even when I breast fed and my son liked one breast better than the other, I became much bigger on one side and it was uncomfortable because it was not symmetrical and it was also out of balance.

Jennifer who had a lumpectomy felt very uncomfortable because her breasts did not match, and Holly commented that even after the reconstruction one breast was bigger than the other. These issues affected their body image and what they considered to be a "normal appearance".

For Julia, the loss of breast and it effect on her appearance, did not appear as traumatic. She was always aware of her "deficiencies" and tried to conceal them. She stated:

> I don't think I had a great body image before the diagnosis. Not that I hated my body but I have a realistic view of my body. I know my deficiencies and consequently I would always be dressing in a manner to highlight the good things and minimize the deficiencies. I always had to dress in a way so it will balance my small breasts and my big hips. And in a way what I do now is an extension of what I did before, although it's far more traumatic.

The treatment that most often affects a breast cancer patient's appearance is chemotherapy. The most dramatic and visible effect of chemotherapy is hair loss, but it can also cause weight gain or loss, and turn a glowing skin into a splotchy mess. Radiation, which is a standard therapy after breast conserving therapy, had some of the same effects on the participants' looks and appearances. Each woman's self-esteem and body image was sorely taxed during chemotherapy and they gave vivid descriptions of the way it affected their appearance.

The seven women who were treated with chemotherapy said that the toxic drug caused a far more protracted hardship on their body image than any surgical treatment they received. Leah said:

> I recovered from the mastectomy fairly quickly. Not chemo, it was hell. It took me down a horrible spiral and I just could not get myself out of it.

Rose recalled:

> When I was in treatment with the chemo, a friend once said to me that I looked so tired. I felt upset. It reflected how I felt inside. I almost felt threatened by it.

The appearance (no hair, looking tired) was an imperfect barometer to the prospects of recovery, but to the women it was more real than a blood test.

Women described weight gain as a major issue of concern and some were still struggling to loose weight a year after they finished their treatments. Loss of hair created drastic changes in their appearance. Some singled hair loss as the most devastating consequence at the time of treatment. Women's reflections on their weight gain and hair loss will be further explored in the following theme which addresses the "Feminine Body".

Concealing the Changes

Appearance is an integral part of body image and while attention to the exterior surface of the body occupies us all, concern with hair, clothing and other dimensions of appearance takes on new importance after visible bodily disruption and a special effort is made to conceal the changes.

Clothing may conceal or it may reveal breast cancer treatments. "I avoid sleeveless tops because of my lymphedema", said Rose. Leah stated that the mastectomy restricted her clothing because "I don't have a cleavage, but I can still wear things with a lower cut because I can wear a camisole, and it's fine". Rose used scarves to hide her chest and Jennifer wore vests. She commented:

> "It's really important for me that I don't put a lot of emphasis on the area of my breasts and draw attention to it. I always cover myself with a vest although I probably don't look that bad. But I'm very conscious of it even if it's not completely true.

For some of the participants, wearing a prosthesis was a satisfying way to conceal their lost breast and retain their normal appearance. The prosthesis made them look balanced in their clothes and, particularly for women with larger breasts, helped prevent the posture, neck, and shoulder strains that can arise due to body asymmetry. Liz stated:

> I don't wear a prosthesis when I'm at home by myself, or when I'm running because it will usually fall out or move all over the place, but otherwise, I don't have a problem with it… I don't find it restricting as far as clothing, it gives me

> a normal appearance, and I realize sometimes that I'm surprised because I don't even think about it.

Leah chose not to wear a prosthesis. She explained:

> Last time I was using what they called a fluffy is while I was having radiation. And one day I was leaving and it fell out and I didn't notice it and kept going and one of the technicians picked it up and handed it to me and I could have died, and I came home and threw it in the garbage and never used it again.

Holly and Mary chose to have reconstruction. Before making their decision to have reconstruction, both women struggled with the emotional issues related to the procedure. Both felt pressured by "others" (mother, friends) not to undergo additional, "unnecessary" surgery. Holly favored reconstruction because she felt that her breasts were important to her appearance and self-esteem. Mary elaborated on the inconvenience of looking after the prosthesis, as well as the way it restricted her clothing. She described:

> I was told that mastectomy will not change any of my wardrobe or what I wear, well, it does. I never was wearing anything that is low cut or anything like that, but after mastectomy you have breast tissue left that is just under your collarbone, and on the other side there is like a hollow, so if you wear any kind of a T-shirt that goes anywhere below the collarbone, you can see it...The prosthesis worked O.K with what I wear as long as you didn't bend forward. The minute you bend, on one side you see the bra, which is O.K, but on the other side you see a dipping away from the body and it is obvious that

> something is missing, and I didn't like it, it bothered me, it made me feel uncomfortable. When I went grocery shopping, I used to think in advance of what I needed to wear, because I knew I'll have to bend down. I didn't like how it preoccupied my mind.

Mary chose tissue expanding reconstruction. She stated: "I didn't get the breast back but I got the shape of the breast. The shape of the breast means a more normal body, with all it's parts. A whole body".

All the women who underwent mastectomy considered the option of reconstruction. Holly and Mary, as mentioned above, chose to have the surgery and others either ruled it out (Leah, Julia, Rose) or still felt undecided at the time of the interview. Liz emphasized that she will consider reconstruction for convenience reasons, but "I will not do it for the look"". She further explained:

> I will not have the tram-flap surgery because I'm not going to damage my stomach area to augment the breast area, that doesn't make sense to me. The saline implant, I know a few people who had it breaking on them, so I'm not comfortable with that, so unless they come with a way of doing it that I think will be effective and safe, I just don't see the need to fill in some fat tissue on this side. The only reason is to be able to wear clothing without having to use prosthesis. The same way as I think, shall I get eye surgery so I don't have to wear glasses or contact lenses. For sport purpose, it's nice not to have to wear prosthesis or glasses.

Julia echoed similar thoughts:

> I don't want reconstruction. I'll never do the TRAM flap. For me, you just screw one part of the body to fix another part. So I'm very opposed to it. There is never an end to it. What other part of the body will you screw up to fix another part?

To conceal the loss of hair, women used wigs, scarves and hats. Jennifer shaved her hair shortly after starting treatment so it would be less upsetting when clumps of hair began to fall out. Liz, Rose and Leah cut their hair very short and even Holly and Julia, who did not loose their hair, but it thinned out, got a short hair cut. Nobody liked wearing the wigs and Liz found the wig more of a burden than helpful. It was too hot and itchy and "felt horrible" and she took to wearing hats instead, but after awhile stopped wearing even that. Rose described:

> When I was wearing the wig outside it felt like part of a costume. I often worried that it was crooked. Usually I was more comfortable wearing a scarf wrapped around my head. I was given some separate bangs of hair which I sewed to the inside of the scarf, so it looked quite natural.

While going through treatment, women were using makeup to conceal the effects of its side effects. Some pointed out that they were more conscious and made more effort to use make-up and improve on their appearance. For Leah, the need to keep a presentable appearance in front of others added a sense of control to a very helpless situation. She described:

> On days that I was coming to the hospital for treatment, I was much more careful how I looked. I worked a lot harder on those days to look as good as I could. At the time it felt like the only thing that I could do to help myself. I

> thought that I was projecting the image of: Yes, I have cancer, and yes, I'm here for treatment, but I don't look that bad. It's not pulling me all the way down. And it was mainly when I was coming here. Going other places it was not that much... I felt so powerless in other ways, so what I could do is may be fool other people into thinking that I looked pretty good.

Holly also emphasized the importance of keeping up her appearance while in treatment. She, referred to the notion of "fooling" other people by concealing her appearance and her real feelings. She stated:

> When I was going through chemo it didn't matter how sick I was in the morning, I still did my hair, whatever I had left of it, and I did my makeup and got dressed. Every day. There were some days when I would rather stay in bed, wishing to be left alone, but I got up and did it every day... Sometimes it took me over an hour to do all that in the morning and my husband would say: why bother, don't do it. But it was important for me. I don't think that I had even one day in these two years that I didn't fix myself up. And before, there were days when I didn't do it, like Saturday and Sunday, who wants to wear makeup? Sometimes it was for myself, sometimes it was for my kids for when they came home from school and they will not see me all pale and blotchy...I needed to look as normal as possible for myself and for other people...It sometimes felt like a double edge. I'm trying to fool them but than I wish sometimes they knew how I really felt inside.

The lack of visible signs of illness created "a double edge" situation and some women commented on the conflict between their efforts to conceal the changes and appear "normal" and the occasional lack of recognition and understanding from others.

The Glance of Others

It was impossible to hide the external body from the view and appraisal of others. Breast cancer brought the body to the focus of others' attention: "It is private and it is public at the same time". Jennifer explained:

> People focus on this area. Lets face it, men look at your bust, and especially if they know that you had breast cancer. I feel that people are always looking at me if they know what had happened to me.

Rose was also very conscious about people's "curious looks" at her breast, and for quite sometime after the surgery used to wear big scarves to cover her bust. Holly reflected:

> My breasts were a feature that made men look at me... After I had the surgery I know people looked at my breasts and maybe compared them to how I looked before.

Mary too felt that at her office she could feel people glance when she bent forward and the prosthesis used to "gap away from the body and it was obvious that something is missing". She continued:

> "It's something that people will not say anything about, but people look, it's human nature, especially if they know that somebody had this surgery, than they look. If you have one leg, they are going to look at the leg".

Several women commented about the experience of swimming in a public pool and having to use common changing rooms, being exposed to the gaze of other swimmers.

Jennifer reflected:

> If I think of going to the pool and having to disrobe in front of other women, I would never do that, never, just because of the way my breast looks. But I used to do it before and now I'm very conscious of it, more than I ever thought I would be.

Liz was also conscious of being observed while changing in a swimming pool. She commented:

> In the changing room, if there are children present, or someone who I feel is uncomfortable seeing me without a breast, I would be very discreet with how I change. I can kind of sense when somebody is uncomfortable.

And Mary added:

> My swim suit was fitting quite well and nobody could tell the difference, but in the changing room, I'm not particularly shy about my body, but all the people around me didn't seem to know where to look anymore.

A woman can disguise, by different ways, the loss of her breast. However, the loss of hair is visible and attracts the attention of others. It involves a public dimension of visibility and therefore "people know that I have cancer". Liz recalled:

> It shocked people to see me bald. I had a waist-long, thick, reddish hair, and people used to see me with long hair since my teens, so they were in a complete shock when they saw me. It was the visible proof that I had cancer.

Jennifer became visibly upset when talking about the loss of her hair. She recalled:

> That was probably the hardest I had to go through. They told me I'll loose my hair, but when it happened it was devastating. It was the reality of the chemo does to you. It was so visible for everyone to see.

And Mary added:

> I was so very conscious when I was wearing the wig. People used to say, oh, I didn't know you were wearing a wig, but I thought that they were being just polite, trying not to make me feel bad.

Julia recalled the "negative attention" she received because of her hair:

> The hair loss was more devastating than the breast. The breast you can hide but the loss of hair is so visible and it's a constant reminder to everybody that you have breast cancer. Even when I felt better during periods of treatments, I still looked like shit because of my hair...I didn't buy a wig because I didn't really loose all my hair, but it came to a point when it was unmanageable. I used to wear scarves but I still looked weird. I remember a waiter who said to me, Oh, I like your hat. It never had been said to me before and it just drew more attention to the fact that I was the only person in the room with attention being given to my head.

Both surgery and radiation can cause lymphedema and a swelling of the arm. An elastic post mastectomy sleeve is one method to help control the swelling. Rose wore a lymphedema sleeve. She stated that the sleeve drew people's attention and she was often asked what happened to her arm and she responded: "Oh, I just hurt it, or I sprained the muscle. I know it draws attention, but I don't always say it's because my breast was removed".

The Naked Body in the Mirror

Physical appearance relates to the way we are seen by others, but also to the way we see ourselves. The scars of breast cancer and it treatment effects can be clothed and covered to approximate normal appearance, but the feelings of being different, disfigured, may remain beneath. The body in private, as self-observed in the mirror, is different to the one that appears to the public eye. Holly explained:

> There is a body image when you are dressed and when you are naked. And when I don't have clothes on it is a constant reminder of what my body went through.

Several women talked about the experience of looking at themselves in the mirror, and confronting their changed body. Holly, who felt very strongly about the changes in her appearance, described her anguish when looking in the mirror.

> "My body image is my naked body in the mirror. When I look at my body now, it's full of scars, and I didn't have one single scar on my body before...I can't tell you how many times I stood in front of the mirror and cried and said: I don't want a perfect tummy or anything like that, Just give me the body I had before."

Liz added: "With my bald head, and all this extra weight, and no breast, I couldn't recognize the person in the mirror, and I didn't like that". And Rose stated: "In private, I really didn't like the sight of my baldness. When I looked in the mirror it reminded me of faces of prisoners in death camps, or photos that I have seen of cancer patients". Some women eschew mirrors to avoid confronting the stark visual changes that have occurred to their bodies. Julia reflected: "I avoided the mirror. I dressed up and turned around only when I was fully clothed". Rose described the "shriveled looking skin" that the radiation left on her chest and how much anguish it caused her, until she was advised of a laser treatment that somewhat improved the look of the damaged skin.

One of the first steps that women took when facing their changed body image was to confront their surgical scars visually. All of them had to cope with scars in some form or another, whether from a lymph node operation, a biopsy, lumpectomy, mastectomy, or breast reconstruction. It was an awkward and uncomfortable process. The first look was never easy, but they all viewed their incisions soon after the operation. For most of the women, the worst scar scenarios they had imagined did not materialize. Although initially upset by their appearance, the more common reaction on viewing their scars was: "It wasn't that bad", "Mine was nice, normal looking scar, it's not ugly".

Liz elaborated:

> When I first came from surgery I wanted to see what it looked like straight away. As soon as they took the bandage off, I was checking it out and I was quite amazed that it looked so good. When I thought it was mutilation and awful, it was before the surgery, before I really knew what they were going to do. The idea that the surgeon was going to cut the breast off was creepy and scary, but when I saw it I realized that it looked quite different.

Karen described her reaction:

> I was not prepared for what I saw after the surgery. After they took out the lymph nodes I thought it will be like a tiny incision but they made a very long cut, and folded the skin and just stapled it and I was horrified when I saw it. I looked like Franklstein, really shocking, but I have to say that it healed well and I only have a fine line and I can probably wear a sleeveless shirt.

But each time they looked in the mirror, the scars were always "a reminder that I'm different, that I had cancer".

The Feminine Body

What does it mean to be a woman with breast cancer - perhaps without a breast, or with a deformed breast? Breast cancer represents a threat of disfigurement and disability, but it is also a female, frequently hormone-related disease, that poses a major challenge to women's female identity. As Rose said: "Breast cancer forces a woman to confront the basic elements of being a woman".

Breast cancer involved a high level of body consciousness and women had to confront the emotional and physical significance of the breasts to their appearance and experience as women. In the present study, the loss of a breast appeared to be more traumatic for some women than others. Their response depended on the way they felt about their breasts and the role they play in their body image, sense of femininity and sexual life. For some of the participants, little value was placed on their breasts, others considered their breasts an integral part of their appearance but not important sexually, still others found them central to their sexuality and appearance.

Holly became visibly upset when she talked about the importance of her breasts. She stated:

> I liked my breasts. They were nice, and they were my best feature...I remember my breasts being a feature that made men look at me. And I felt really good about it. I liked to wear tight T-shirts and sweaters that emphasized my breasts and my husband liked it too.

Jennifer, who underwent lumpectomy, felt that a "breast is a big part of a woman" she stated:

> When I think of myself as a woman with this kind of a breast, I'm really unhappy with myself. We know that as we age our breast sag, so it didn't do me any favor with the lumpectomy that left me with one breast which is high and conked and one which is normal...I never realized how much it will bother me as a woman, not the fact that I don't have two breasts, but that they are not the same.

Other women commented that "breasts are big part of being a woman", but loosing a breast did not make them feel "less of a woman", as Mary stated: "The physical part of my body changed, but not the way I feel about it. I don't think of myself now as less of a woman". And Liz commented: "My femininity did not rest in my breasts. To me, being a woman has more to do with how I feel inside than my breasts". Rose echoed similar feelings: "My looks may have changed, but the other qualities I associate with my femininity haven't".

Cultural associations of femininity with breast size, cleavage, and clothing were brought up by all the women that participated in the study. Remarks about "lopsidedness", and "no cleavage" were made by women who underwent mastectomy and were described in the third theme (the visible body) in relation to their appearance. They were manageable issues for some, and marginal issues for others. Prostheses replaced the lost breast and created the appearance of two breasts - normal femininity - so that "others cannot tell which is which".

Holly and Mary chose to have reconstruction surgery. Holly talked about the convenience of not having to look after the prosthesis, but she mainly emphasized the need to regain her feminine appearance, wanting "to go back to having a sexy bra and panties to match". She was somewhat disappointed with the results of the surgery. She stated:

> I wanted a cleavage, which I don't quite have, and for some reason I didn't expect a scar around the whole breast. I also wanted to stay a size D, and now I'm smaller because they had to cut so much out, and, of course, I don't have a nipple... There is no sensation in the new breast at all, I can feel the chest underneath, but I can't feel the breast...I'm also scared about reoccurrence, because now I have this mount of fat covering the chest and I wonder if it will be more difficult to detect it.

But she was happy with the fact that she "looks normal", and can wear a negligee, and although the reconstructed breast had no sensation, she could not feel the prosthesis either, but now "I have a breast which is part of my body, and I feel more comfortable and feminine". Mary hoped that reconstruction "will take care of all the clothing things, no more hustle about where is my prosthesis, taking care of it, how is it going to fit in different bras".

Most of the women felt that their femininity had not been compromised by their breast surgeries, but the temporary chemotherapy effects were very taxing to their appearance and sense of femininity. Loss of hair and weight gain were a major concern to all the participants who received chemotherapy. Women consider thinness as an essential and basic element of physical attractiveness. Weight gain was an issue for every single woman who received chemotherapy. Holly recalled:

> Weight was always important for me. After the surgery, I remember, and this sounds terrible, I remember thinking, I hope chemo makes me loose weight. I ended up gaining weight. I gained almost 40 pounds. I looked puffy and my muscle tone changed and it made me depressed and anxious. I didn't like myself as a fat woman.

Liz who was very involved in sport activities found the weight gain a particular source of concern. She stated:

> With the chemo I got to 178 pounds and that was devastating. Being so heavy was worse than not having a breast. My face was so fat that my eye glasses were digging to the side of my temples.

Her definition of femininity was closely related to loosing weight and having an athletic and strong body. She explained:

> The issue of having a sculptured breast is not the major point. For me, if I was super athletic, looking with or without one breast, I would look and feel feminine and sexy. I would come across as a beautiful woman, because my body is toned and fit, whether I had one or two breasts. And people will say:

> Oh, she has one breast, how can a woman with one breast look so beautiful, it's amazing!

In our culture hair is used as an indicator of personality, attractiveness, sexuality, and femininity. Jennifer became visibly upset when she recalled the loss of her hair. She described how she lost her hair from the entire body and the way it affected her.

> I lost my hair with the chemo. It was the hardest thing I ever went through in my life. I'll never forget what it felt like when my husband shaved my head…I lost my hair through my entire body (crying), and it was so weird to go through it. Even the fact that I didn't have to shave my legs didn't sound funny.

For Liz, loosing her hair had a special significance as it was closely related to her sense of femininity. She explained:

> When I grew up and was around 12 or 14, I looked like a boy and people mistook me for a boy. I had a deep voice and I looked like my brothers, and my mom cut my hair short, pixy cut, so I got used to think that if I had short hair I would look like a boy, and therefore I let my hair grow and kept it long… And to not have a breast, and having no hair, I didn't want to be seen as a boy. My young cousin saw me when I was bald and he said, 'Oh, she is beautiful,' and that meant a lot to me that I still looked feminine and beautiful even without hair… Now I know that you don't become a man because your breast is gone and your hair is short.

Julia, as well as Jennifer, described the importance of hair to their appearance and sense of femininity. Julia recalled:

> For me hair has always been an issue. Always fussing with my hair before I go out, feeling it is such an important thing for me, to the way I feel in general... The hair loss came in a way at a bad time in my life. I started to feel like I was aging a bit more and when you have no hair it augmented the whole thing.

As described by all the participants, breast cancer and it treatments had an impact on women's sense of femininity. At times they felt scared, ashamed and insecure about their bodies. They were forced to confront the basic elements of being a woman, but none felt that she "lost her femininity" or became "less of a woman".

The Intimate Body

The intimate body integrates physical, aesthetic, mental, and emotional dimensions of lived experience. It includes intimate relationships with partners and sexuality. Sexual intimacy in this cluster is broadly defined to include all touching behaviors, of which sexual intercourse is only one. Meanings of the intimate body are already tacit in the preceding themes, particularly the feminine body with its implications for a woman's sense of looking attractive and feeling desirable.

The same, but different

Six women who participated in the study were married, and two were separated from their husbands. Regardless of the kind of treatment they received, every woman was understandably concerned about the impact breast cancer would have on her relationship with her partner. Couples cannot go through such a life-threatening crisis together and not undergo some level of change in their relationships. In fact, all of these women felt that their partnership did change, both emotionally and physically. All the women involved in intimate relationships received strong emotional support from their partners. The crisis brought the couples closer together, rather than moving them apart, enhancing and strengthening their relationships. None expressed concerns that their husbands would leave them, however they admitted to some anxiety over their husbands' reactions to the surgery. Holly recalled:

> I remember when I came home, I turned my back when I changed, and I didn't let my husband look at the scar. I'm not talking long term, may be a week or so. I just didn't want him to look at it. And my husband had a hard time understanding it. He didn't have this shocked look on his face. He just looked at it and kind of shook his head and said OK and that was it.

Liz stated that she showed the scar to her husband immediately after the operation. "As soon as I saw it, he saw it too. He didn't like the tubes coming out of my chest, but I didn't get the reaction about the breast itself".

Leah is married to a man who is younger than her by eight years. It is also her second marriage. She recalled being very concerned of his reaction to the surgery. She recalled:

> He didn't see it at all when I first came from the hospital. I was very private and I needed to come to terms with how I looked before I shared it with anybody else, even with him. So about a week later, when I went to the surgeon to check my stitches, it was the first time he saw it, and he physically drew back as if something hit him. He was shocked because that was not what

> he expected, however he imagined it to be. So of course that made me feel not good at all. But he got involved right after that and wanted to help.

Some of the women felt that although the experience of breast cancer enhanced their relationship with their husbands, the surgery has affected their intimate relationship. There were subtle changes in their husbands' responses, and there was their own level of comfort in moments of intimacy. Holly described:

> My husband never touched my mastectomy scar and that really bothered me. Right up to the reconstruction he never touched it. We make love and he only touched my good breast. It bothered me and I did ask him and I remember taking his hand and once and putting it there and I said, you don't have to be afraid of it, it's part of me now, but it was the only time he had his hand on it. He said it didn't bother him, but he still couldn't touch it. And we never dealt with it, and come to think of it, he never touched my new breast either.

Unlike Holly, Jennifer remarked that she was the one who was very self-conscious about the changes in her breast and therefore felt uncomfortable when touched. She stated: "My husband touches my breast, but it bothers me, I wonder what he thinks. But it doesn't seem to bother him".

Leah felt that there has been a change it her sexual relationship with her husband. She considered it to be a " big loss for our relationship. We were only married for seven years before I was diagnosed and the sexual part was very important in our marriage and it changed. That was a big hurdle to overcome". She further reflected:

> For many months, especially when chemo was going on, he really tried to be his old type of self, but it was not working. Before, he used to playfully grab me and things like that, but it was not happening any more. We did talk about it and agreed that we cannot pretend that things are the same the way they were before, but we have to carry on in a different way…Part of our relationship is different, I guess, foreplay is different. My breast is still sore, so he doesn't touch it. He talks to it, and he treats the sick one like a baby, saying he hopes it gets better, but he doesn't touch it. I think he knows that it still hurts.

Leah distinguished between the sexual part of their relationship and the general feelings of intimacy that they felt towards each other. Although the sexual part had changed, the intimacy "grew ten fold". She also described the need to be reassured by her husband that "as much as things changed, they still stayed the same". She said:

> As far as the intimacy is concerned, it brought us even closer. I truly feel appreciated and loved. Really cherished… As far as the sexual part, it affected me very much at the beginning because I felt that I let him down because I got cancer and I thought that he will not feel the same about me because of the way I looked. I learned later that I was wrong. Yes, he was affected by the way I looked, but that was not going to change the way he felt about me, and it took my husband awhile to get it through my head. There was no denying that he liked the way I looked before, and yes, he was sad for the way I had to look now but it doesn't affect his love for me and he was not with me because of my

> breasts, and that made me feel better about myself. I know it now, but I needed to be reassured many times.

The hidden body

The women in the study felt very self-conscious about their naked body while in intimate situations. The level of comfort that had developed through years of partnership, seems to have changed. In their intimate relationship, each woman experienced a need to cover and hide her altered body. Jennifer stated:

> I think that it affected our intimate relationship. Now I would never go to bed with no clothes on. I used to go around the house naked, or lie beside my husband without clothes but now I feel uncomfortable. We never really talked about it, but I think he must feel it.

Leah, Julia and Rose described some similar feelings. The changes were most apparent after surgery and while in treatment, but became less noticeable in the long process of recovery. Leah remarked:

> I didn't undress in front of him for a long time, like six months or so. I was getting very good at undressing in the same room but at the same time turning away.

And Julia stated:

> I'm kind of a modest person and because I was never particularly proud of my body, I was never totally comfortable walking around naked, but now I wouldn't do it. I'll undress in front of my husband, but I'll make a point not to spend a lot of time like that because that doesn't feel comfortable.

Rose described how her naked intimate body gets hidden:

> In bed, I just don't feel as sexy as I felt before. There were things that I wore to bed that I don't wear any more. After the surgery I started to wear pajamas because I didn't want him to look at me because I didn't think I looked good. Now I'm back into the 'nothing', the way I was before, but I still like to cover myself if I think we are going to have sex because I don't think I look very appealing.

Being sexually intimate

There are both emotional and physical problems that women faced that may have affected their sexuality. In addition to the loss of a breast, there are many treatment-related problems that can impact their sexual life: physical limitations from the surgery, pain, limited arm movement, hair loss, weight gain, vaginal dryness and possible loss of sex drive as a result of chemotherapy. For some women chemotherapy caused premature menopause. Not all women offered to share their experiences with sexuality. Perhaps such sharing was too personal and private, or perhaps for some women, sexuality was of a lesser significance in the overall experience of breast cancer.

As would be expected, because of the tremendous emotional and physical demands of surgery and treatment, the sexual aspect of their intimate relationship changed for many women. Intimacy did not end, but the amount of sexual activity during and after treatment varied among the women. Rose said that "sex was the furthest thing on my mind" but Karen resumed her sexual life shortly after the mastectomy.

Rose described how loss of hair affected her sexual life: "Loosing my pubic hair was very difficult. It made me feel naked and embarrassed, like a prepubescent child…I felt too exposed and I didn't want to be touched". Later she found that she lost her period, and that she had stopped lubricating when she became sexually aroused, and it made her confused about her feelings of sexiness and sensuality. Leah described the side effects of the treatment on her sexual feelings. She said:

> Our sexual relationship in general was affected for awhile, but I honestly think that the treatment was a big part of it. When I was on chemo I felt so tired, nauseated, I couldn't stop eating, just the general feeling of feeling unwell. I just didn't feel like having sex. And it lasted for about a year until the treatment finished.

She continued to describe the changing sensations in her breast:

> My breast is still sore, and he doesn't touch it. There is a lot of muscle damage and the bottom part seem to pull, so it hurts. The sensation is not bad, but even during arousal the nipple doesn't respond the same. It seems to hurt in the inside, not like when I used to get my periods, and the breasts used to ache. It's not that kind of a hurt, but it feels like it's coming from deep inside.

Karen had a lumpectomy. She refused to accept the surgeon's recommendation to remove the nipple because of its sexual significance. She explained:

> For me the nipple can be compared to a penis, in that that there is such an obvious sexual sensation. It's not the breast or the size of it, but it is the existence of the nipple. For me just a breast without a nipple is like a lump of flesh and it would be almost revolting.

She was prepared "to do anything to try and conserve this nipple…I tried to explain to

> him that it will be a very great loss for me, a considerable greater loss to loose the nipple than the breast. If he left the breast and not the nipple, he might as well take the whole breast off".

She got her message through although she felt "almost silly to hang on to that, and risk my health". The results were not completely satisfactory. She described:

> It's not the way it looked before. It's sort of tucked in and it doesn't really work because it doesn't get erect, and I don't know if it will come back with more healing. It's like the rest of the area, it feels kind of numb… But I am kind of satisfied with the way things are. If it stays like this forever, because I have a breast and a nipple.

Even with the negative changes that occurred in their sexual lives, women continued to have stable relationships with their partners, and were intimate, often in different ways. Women who shared their experiences in the area of sexuality reported satisfactory sexual relationship after the treatment was completed.

Integrating body image into the self

The women in the study had to accept the changes that have occurred in their body and integrate the new image into the self. Bodily acceptance is viewed as a road to integration and the journey was experienced by each woman. As Holly stated: "It was a process that started with the diagnosis, till the place where I am today, and I'm still not at the end of the road."

Grieving the losses

The most recurrent theme that emerged from the conversations with the women of this study was that of loss. They described visible and invisible losses, large and seemingly small, but they all needed to be grieved.

Perhaps the most obvious concrete loss to the women in this study was the loss of their breast. It created a change in appearance, and forced them to re-examine their feminine and sexual identity. What mattered even more than the physical loss was the highly personal meaning of what has been lost. Some women chose to use prosthesis to create normal appearance, two women chose breast reconstruction, while for Leah, part of the enduring meaning of loosing a breast was embodied in what was now missing. For Leah, who refused to wear a prosthesis, life without a breast was part of her larger commitment to realism. She stated:

> I don't need to hide it and I don't want to erase anything because I don't want to forget. I got through it but I can't fall into the illusion that I beat it and everything is the same as it was.

One woman's defacing scar is someone else badge of courage. Jennifer and Julia did not like the look of their scars. Leah referred to it as a sign of "triumph" and Karen as a "kind of trophy. It reminds me of what I went through, and I'm still here". Rose called it a "worrier scar, the result of a hard battle".

Other physical losses included loss of hair, weight gain, and restricted mobility of the arm. They created functional problems that were so oppressive as to crowed out other considerations for a time. There were also permanent physical changes as a result of the chemotherapy. Liz who went through early menopause talked about feeling "physically older" and stated that she was not ready to be ten years ahead of her biological schedule.

There were also intangible losses like loss of control, choice, and trust in their own bodies. Julia recalled the day she was wondering around the store and saw a bikini and thought that she will never be able to wear it again. She reflected:

> But even 10 years ago I probably would not have dared to wear such a bikini, so why do I even think about it? But, of course, now I lost the choice to wear it even if I wanted, and that's what makes all the difference.

Liz was grieving the loss of her long beautiful hair. She got used to, and even liked her present short hair-cut, but "it was not originally my choice".

Holly, Liz and Rose talked about a sense of alienation from their own bodies, as if the bodies have disappointed them in some essential way. Holly talked about a sense of "betrayal" by her own body, and Rose felt that she "lost trust " and did not feel safe in her own body.

Creating changes

All the women that participated in the study concluded their stories detailing the changes that have occurred in their life after experiencing breast cancer. The value of nurturing themselves became a priority. All the women believed that what was critically important in their lives was to take care of themselves first, an item that for many had been low on their priority list before having breast cancer. Leah talked at length about self-care as a fundamental change that have taken place in her life. She described:

> I can't say so much that things happen for a reason, especially when I can't find a reason for the cancer happening to me, but I learnt that it was time to start looking after me, to slow down, it was time for me to get back to me. I can easily fall back and carry on charging through life the way it was, when everybody comes before me, but I have a missing breast and a scar to remind me not to do it.

The experience of cancer made her lose the illusion of a secure future. "This is a sign that life doesn't go on forever". She further reflected:

> When you are 40, you think you have another 40 or so years left, so I can devote my life to my family, and later on I'll have time to look after myself. But now I don't think I have so much time left, so I'll better focus on myself now… I have taken a course in meditation and it helps me to relax and feel centered and calm. Now I'm more in tuned with what I want at the moment. So if what I really feel like doing now is sitting down and reading a book, or if I feel like taking a nap, that's what I do, and I did very little of it in the past.

Changes in diet and exercise were echoed by every single woman. Jennifer described:

> I decided that I have to get myself healthy again emotionally and physically and it became the most important thing in my life. I started working out and watching what I ate, I lost 20 lb. And it was the best thing for me. I exercise and run and drink less. My life style has changed.

The experience of cancer created changes in the way women felt about themselves. Holly stated: "I'm a different person now. Completely different. And very positively different. I'm stronger, my priorities are different, and I'm not scared to say what's on my mind". Liz felt she became mature beyond her age: "I feel like I'm 10 years older. And people say they forget I'm only 40". And Rose reflected:

> Breast cancer opened up areas of my life that as a woman I really didn't explore before. I can see now that I'm many parts and many things. It includes my sense of independent and dependent, being soft and feminine but also assertive, being attractive and sexual. So now I can see that there are different ways to be a woman.

Women were renegotiating intimate relationship. There were inevitable changes and transformations that occurred because of the experience. However, the women felt that the experience brought them closer to their husbands, as Leah stated: "I feel truly appreciated and loved. Really cherished". Liz felt that her relationship became more of a partnership, " you realize that this person is with you and for you on different levels".

When asked to describe how they feel about their body image at this point in time, women responded with an overall positive attitude, although they were not necessarily at the same place in their process of recovery. Liz described:

> We recently went on a holiday. When I put on a pair of shorts that I didn't wear for a long time, I said to myself: Oh, I look so good. There were a lot of mirrors in this hotel, and I looked at myself and liked what I saw. I looked healthy and really good and happy.

Jennifer echoed similar feelings: "I look better and feel better and even my husband says to me how better I look now, which makes me feel really good". Leah considered her recovery as a personal triumph: "I can actually look at myself now and say: I did it.

I got through it. It was not easy, but I made it and I think I did it pretty well". Mary and Holly were still in the process of completing and recovering from the breast reconstruction, but they were satisfied with the decision to undergo the extra surgery and were optimistic that the results will justify the procedure.

In concluding the interviews, all the participants remarked that adjusting to the changes in their body image is a continuing process. Deeper changes only come in time. As Holly summed it up: "I have come a long way, and I'm still not at the end of the road".

The themes presented in this chapter had qualities universal to all the participants, yet variations and individual characteristics did emerge. These themes addressed by the women related to the issues of breast loss and changes in body image caused by the treatments for breast cancer, from the time of diagnosis, through treatment, and on to their later recovery. In the following chapter, the thematic analysis is reviewed and discussed in light of the relevant literature.

CHAPTER FIVE

DISCUSSION

Women's perceptions of their altered bodies after undergoing treatment for breast cancer was explored in the present study. In this chapter, themes that have emerged from the data are compared and integrated with current literature and reviewed research. An attempt was made to suggest how existing literature might be understood in light of the findings, and to propose new ideas that could better account for these findings. The study's limitations followed by suggestions for future research are presented. A section on practical implications for health care professionals follows, and the chapter ends with the study's conclusions.

In an attempt to describe women's perceptions of their changed bodies, five major themes which account for all of the stories shared by the participants, will be discussed in the present chapter. These themes include: body image as a personal perspective, the body as a physical experience - incorporates the body as an object and a functioning instrument, the public body - includes the visible and observed body as it appears and presented to others, the private body as an expression of self - refers to issues related to feminine identity, intimacy and sexuality, and the fourth theme describes women's reflections on reintegrating body image into the self. These themes represent an attempt to capture women's perceptions of their body image. At the same time, it should be stressed that these themes do not form fixed categories. Rather, there is an interplay between and among the themes, and each domain implicates all others.

Body Image - A Personal Perception

Audre Lorde, in her book The Cancer Journals (1980) states:

> Each woman responds to the crisis that breast cancer brings to her life out of a whole pattern, which is the design of who she is and how her life has been lived. The weave of her everyday existence is the training for how she handles the crisis (p. 9).

Intertwined in the breast cancer stories were women's reflections about their past experiences that shaped and influenced their perceptions of their bodies. Body image is individually created by women based on their unique histories, life circumstances, and particular contexts. Messages from family, culture, society, and the media are incorporated into the self-image. However, women are not passive recipients of their cultures. These messages are taken in and accepted to varying degrees by each woman. This is why the same event or experience does not have the same meaning for all women. This would also help to explain why the same body part (e.g., breast) might mean different things to different women. Several factors seem to be implicated in the degree to which any woman accepts the messages and meanings promoted in her social world in constructing her body image. These factors include the persistence of the messages, the woman's investment in the opinions and beliefs of the messenger, her values, the source of the messages, her age and life stage, and her current self-image (Daniluk, 1998; Fallon, 1990). To understand how women perceive and experience their bodies, it is important to focus on each woman's unique history, and on the contextual, situational, and relational realities of her life.

In the present study, through in-depth interviews, participants' perception of their altered body emerged from within their life stories and their experiences with the disease. Eight stories discussing body image and breast cancer revealed body image which was unique and personal. It was the product of the messages of their bodies and of their environment, interpreted through the lenses of the values and beliefs, they had come to hold. Each of the women interviewed for this study reported a change in her body image as a result of being treated for breast cancer. There were physical changes that affected how her body functioned, changes that altered her appearance, and intangible changes that concerned her body-integrity and self-image. The meaning attached to the experience was different for every woman and reflected the individual interpretations attached to the disease and the resulting changes.

However, the subjective data of each woman's account did not stand alone as isolated phenomena. Rather, the features of the subjective experiences of one woman were frequently shared among other women. When analyzing the data, it was remarkably clear that certain experiences, feelings, and beliefs had qualities universal to the entire group yet, with individual characteristics. The themes that emerged from women's experiences although subjectively defined were often communally shared. They depicted the impact breast cancer had on women's body image and the process involved in re integrating the altered body into the self.

The Body as a Physical Experience

Body image problems result not only from the loss of a body part or other disfigurement, but also from the additional loss of body function. A woman's perception and appraisal of how her body functions is an integral part of her body image. In the present study, the women described their bodies in relation to its function, that it, what biological and characteristic activities it enabled them to perform. Treatment related problems, such as physical limitations from surgery, pain, and fatigue disrupted their daily activities and interfered in their functioning. The women described limitations in physical and sport activities, and restrictions on the body's movements. Their descriptions also challenged the reduction of breasts to their mere appearance. Breasts were talked about in relation to their nurturing (breast-feeding) function, as well as a body part supporting the whole body's movement. These findings were consistent with other research which reported women's concerns with the physical and functional limitations imposed by the treatments (e.g., Ferrel, Grant, Funk & Garcia, 1997; Ganz, et al., 1996; Kiebert, de Haes & van de Velde, 1991).

Pain and illness are experiences in which a person often reports becoming aware of an object quality to the body. The body is experienced as an object whenever there is a need to ease, limit, or avoid pain (Pollio, Henley, & Thompson, 1997; Seymour, 1998). In the present study, each woman at the time of diagnosis, described a profound fear of death and the issue of loosing a breast was subordinate to issues of health and survival. The emotional and cultural meanings of breast cancer received little consideration at this time. The breast became a separate body part, an object to be conserved or lost, but detached of any aesthetic, functional, feminine and sexual meanings. The breast was often referred to as *it*, and characterized as a *limb,* which de-emphasized the uniqueness of breast cancer in distinction to other cancers.

The objectification of the body was further reinforced by the voice and practice of medicine. In the development of western thought and medicine, the body came to be regarded as a machine and the doctor is the mechanic or technician who "fixes" it. As such, this approach ignores the emotional parts of the self and promotes fragmentation of body and self (Martin 1987). Young (1990) states that the diseased body is treated as an a object, a conglomerate of fixable or replaceable parts, and the breast is considered detachable, dispensable. Under the medical gaze the body becomes an object, devoid of personal identity and separated from the self, contributing to a fragmented body image. Batt (1994) further argues that the detached, highly abstracted medical language gives little insight into a woman's lived experience and creates higher walls between doctors and patients.

In the present study, most women described how medicine, through its language and practices, reduced them to a patient with a potentially deadly disease, located in a specific, discreet body part, the breast. Several women talked about their body undergoing medical treatments, as separate from the self. One felt "exposed, like on a stage, with the audience free to question, examine, inject, and cut" and another remarked that "the body is just a house we live in, and it's been treated, but not the actual person inside". Some recalled "feeling numb" and "detached".

Van Manen (1998) in his discussion of the body experience in illness and health, asserts that every person is challenged to develop a livable relation with his or her body in the world. The ill person, who for reasons of circumstance is out of step with the body, may feel alienated in his or her embodied being if body experience and situated experience are in conflict or disharmony. When a woman diagnosed with breast cancer seeks medical advice, she is prepared to objectify her body and submit it to medical scrutiny. However, if the physician only has regard for her body as an object and forgets that she is a person who *is* this body, then she may experience alienation: alienation from human relation and alienation from lived body relation. Van Manen (1998) concludes that increasing awareness of health care professionals can help the ill person develop meaningful relations between the physical body and the lived body, "between the embodied being and the world" (p. 24).

The Public Body

Physical appearance is a conspicuous aspect of the self, both in the way we see ourselves, and in the way we are seen by others. These two perspectives are inter-related but separate (Cash, 1990). The external body presents itself boldly to the world and it is subjected to the view and appraisal of others. The outside of the body is a public property. Others see the external body and may make assumptions about it, with or without our approval or knowledge. They can also relate external appearance to the essential nature of the person and its personal qualities (Cash, 1990; Seymour, 1998). Therefore, other people are important agents in the development and maintenance, and in the destruction, of self-esteem (Cash).

In the present study, breast cancer treatments caused changes to the body and brought increased body-consciousness to all participants, regardless of type of treatment they received. The most visible effect of chemotherapy was hair loss, as well as weight gain and skin discoloration. Breast surgery created asymmetry and, in the case of mastectomy, caused a visible distortion in normal appearance. Women reported feeling exposed under the gaze of others and were conscious of others "curious looks", particularly in places like swimming pools. These findings were supported by extensive body of research which studied women's reactions to the side-effects of the different treatment modalities (e.g., Fallowfield, 1996; Keibert, de Haes & van de Velde, 1991; Levy et al., 1992; Mock, 1993; Schover, Yetman & Tauson, 1995).

Seven women who were treated with chemotherapy said that the toxic drugs caused a far more protracted hardship on their body image and self-image than the surgical treatment they received. Hair loss was described as a "most traumatic experience" and some singled it as the most devastating consequence at the time of treatment. The loss of hair involved a public dimension of visibility and a loss of privacy. The invisible, silent disease became visible, and as one woman stated: "with the loss of my hair, people knew that I had cancer". The eyes of others reflected their feelings and fears about cancer and mortality. Two studies which explored the effects of hair loss on breast cancer patients reported similar findings (Baxley, Erdman, Henry & Roof, 1984; Freedman, 1994). Freedman conducted a qualitative study to examine the symbolic meaning of hair loss in breast cancer patients. She concluded that the women in her study experienced much more than the loss of hair. Alopecia symbolized loss of privacy, individuality, and identity.

When diagnosed with cancer, chemotherapy agents are sometimes used to give a woman a greater opportunity for improved health. They are used to cleanse the body of invisible but potentially lethal cancer cells. In fact, the goal of chemotherapy is to cure the patient of a life-threatening disease, or at least, to put off the immediacy of the life-threatening nature of the disease. However, hair, as indicated above, has a symbolic meaning as an indicator of personality, attractiveness, sexuality, and femininity (Freedman, 1994, Pickard-Holley, 1995). The consequent loss or thinning of hair contains such powerful societal meaning that experiencing the hair loss as part of a life-giving process is rarely acknowledged by women (Freedman). The reality of death is less real than the image of baldness. What counts is sustaining the image today. Several women who stated that at the time of diagnosis, their primary concern was for health and survival later became conflicted. They began to voice equal or primary concern to how they would look. As one participant stated: "I guess body image was a big deal…and I hate to admit that because it sounds so trivial and so ridiculous". For participants in the study, hair loss at the time of treatment was more of a topic of concern than fears of the treatment not working. Some researchers described it as defense mechanism: the greater fear of death is displaced onto the lesser (Penman et al., 1987; Polivy, 1977). On the other hand, the integration of the deep reality of the meaning of cancer most often occurs over time, and perhaps for some women whose identity truly is "for today", the immediate side-effects on body image are the greater fear and body image is truly the most pressing concern at that particular time. Kasper (1995) conducted a study on women with breast cancer and offered a feminist interpretation to the conflict between medical issues of health and survival and cosmetic outcome of treatments. She suggested that this seemingly absurdity occurs because the culture has established a profound connection between women's appearance and self-worth. Women with breast cancer find it difficult to disentangle the twin issues of survival and cosmesis because they sense that in society's calculus of women's worth, a great emphasis is put on appearance. To lose a breast or hair, then, poses not only the threat of death but the loss of the self as well.

In western society it is accepted that the cosmetic, the costume, and the disguise play an important role in maintaining a normal appearance. A vast array of dietary, slimming, exercise, and cosmetic products point to the significance of appearance and bodily presentation. Looking perfect and wearing socially approved garments is the path to normalcy and belonging (Wolf, 1991). Not surprisingly, women in the study tried to conceal the changes that have occurred in their bodies and appearance by using costume, make-up and wigs. These forms of disguise created a situation where women did not have to relate to others about their cancer, but at the same time made it difficult to evoke understanding or help. Audre Lorde (1980) argued that restoring the normal appearance simultaneously keeps women with breast cancer hidden not just from the other's gaze but from each other. They also create a system of protection for other people in which they shield them from their own vulnerabilities.

Women in the study, reported making a special effort to conceal the changes that have occurred in their bodies. Some stated that while in treatment, they were paying more attention to their appearance than before they were diagnosed with cancer. In a world filled with uncertainty, controlling their appearance gave women a sense of competence and renewed control over their bodies. Taylor, Lichtman, and Wood (1984) studied the effects of attributions, beliefs about control, and adjustment to breast cancer. They concluded that the illusion of control both helps people handle extremely stressful situations and makes them persistent in pursuing their goals.

Women in the study, by trying to conceal and disguise the changes in their appearance, gained a sense of control which was associated with adjustment.

The Private Body as an Expression of Self

What does it mean to be a woman with breast cancer, perhaps without a breast, or with a deformed breast, without hair, or overweight? Breast cancer represents a threat of disfigurement and disability, but it is also a female, frequently hormone-related disease, that poses a challenge to women's female identity and sexuality.

Throughout life women encounter varying life experiences where the distinctions between culturally-imposed themes and personal meanings become particularly clear. A breast cancer crisis is just such a life event - the competing public and private meanings associated with breast cancer are often dramatically, and painfully, revealed. More precisely, women diagnosed with breast cancer often discover that the social assumptions which define them as women no longer match their own interior definition of what it means to be a woman (Kasper, 1994).

In western culture, women's breasts have long been valued for their aesthetic, feminine, and sexual worth. Hair and weight are also used as an indicator of personality, attractiveness, sexuality, and femininity. Through the process of female socialization many women come to believe that to lose a breast is to lose one's identity and sense of self as a woman. If a woman accepts the role that society has created for her, and if she has been conditioned since childhood to measure her worth in physical terms, the loss of a breast and changes in her appearance threaten every fundamental component of her identity: her self-image, her femininity, and her measure of herself as a person (Maldonado, 1995). Indeed, several studies found that women with breast cancer whose breasts play a significant role in their appearance or sexual life may suffer a greater loss and have a more difficult time dealing with their new body image (Fallowfield & Hall, 1991; Schag, Ganz & Polinsky 1993).

In the present study, women reported that the loss of a breast to cancer was a violation not only of their physical integrity, but of their private and public identities as women. Their degree of distress varied, but it was never neutral. The fact that many women in this study struggled with their appearances to themselves and to others prior to breast cancer, only set the stage for the sense of violation and loss many felt when the cancer was diagnosed. However, the loss or alteration of the breast appeared to be more traumatic for some women than others. Their response depended on the way they felt about their breasts and the role they played in their body image, sense of femininity and sexual life. For some participants, little value was placed on their breasts, others considered their breasts integral part of their appearance but not important sexually, still others found them central to their sexuality and their appearance. As indicated in the literature review, a large body of research examined the effects of mastectomy versus lumpectomy on women's body image and reported some conflicting results. In the present study, six women underwent mastectomy, and only two had lumpectomy, however, all the participants expressed concerns over their altered breasts.

Meyerowitz and Hart (1995), in their article "Women and cancer: Have assumptions about women limited our research agenda? " argue against the implicit assumption that breasts are so central to womanhood that any assault to the breast will destroy women's psychological integrity. They further claim that this view is an overgeneralization, based on popular cultural standards by which to judge a woman's femininity, rather than on empirical evidence from patients. The misconception that breast loss is central among *all* mastectomy patients' concerns can lead some patients to feel misunderstood and unsupported. No woman takes the loss of her breast lightly, yet the effect of the loss may be different for every woman, depending in part on how much of her self-image comes from the physical self. One woman's significance loss can be considered an inconvenience to another. As described above, women in the present study expressed different degree of concern to the loss of their breast. At times they felt scared, ashamed, and insecure about their bodies. Some strongly associated the loss or altered breast with issues of femininity and sexuality, and others held it less important than health and an active physical life. It was clearly these women's *own* definitions, all of which were different, whether they felt feminine or womanly, but none reported feeling that she "lost her femininity" or became "less of a woman". As one participant remarked: "The physical part of my body changed, but not the way I feel about it. I don't think of myself now as less of a woman".

Research findings indicate that body image and sexuality are the two areas of psychosocial functioning where problems do not appear to abate over time, even for disease-free patients who are well adjusted in other domains (Schag, Ganz & Polinsky, 1993). In fact, there is some evidence that sexual functioning may actually worsen (Ganz et al., 1996). Women in the present study reported that they felt very self-conscious of their naked body, at times ashamed of the scars, feeling insecure of their sexual attractiveness, and feeling a need to cover and hide their altered body. Because of the tremendous emotional and physical demands of surgery and treatment, the sexual aspect of their intimate relationship changed. In addition to the disfiguring surgery, there were other treatment-related problems that impacted their sexual life: physical limitations from the surgery, pain, limited arm movement, hair loss, weight gain, vaginal dryness, and possible loss of sex drive because of the chemotherapy and premature menopause. Intimacy did not end, but the amount of sexual activity during and after treatment varied among the women. These findings were consisted with a large body of research that reported negative impact on sexual functioning after treatments for breast cancer (e.g., Ganz, et al., 1996; Omne-Ponten, Holmberg, Bergstrom & Burns, 1994; Polinsky, 1994; Schag et al., 1993; Schover, Yetman & Tauson, 1995; Wellisch, 1985). Not all women participants offered to share their experiences with sexuality. Perhaps such sharing was too personal and private, or perhaps for some women, sexuality was of a lesser significance in the overall experience of breast cancer.

Reintegrating Body Image Into the Self

Women's body histories are fluid and changing. Whenever changes occur to a woman's body, be it childbirth, menopause, or treatment for breast cancer, she has to redefine her identity as a woman and integrate the changes into her self, based upon her new physical and mental image of herself (Maldonado, 1995). A woman's response to her altered body after treatment for breast cancer reflects the value she assigns to the bodily change and the response of significant others in her life (Kahane, 1995). Women who confront breast cancer also confront the clash between how society values women and how women value themselves (Kasper, 1995). To a large extent, reclaiming body image after breast cancer rests on each woman's ability to renegotiate her sense of self in spite of, and in opposition to, society's cultural views of women (Kahane).

The challenge of breast cancer is the challenge of change - not the slowly evolving change that we associate with life, but the sudden change that drops suddenly like a death sentence. However, having cancer is not a one-time event but an ongoing process of growth and change in which women learn to live with altered bodies, fractured identities and disrupted life. The women in this study are at different stages of integrating their bodily changes into their self-image and self-identity, and this research captures only a part of this continuing process. Deeper changes only come in time. As one participant remarked: "It was a process that started with the diagnosis, till the place where I am today, and I'm still not at the end of the road".

A sense of bodily acceptance is an important factor in the experience of integrating the changes into the self (Seymour, 1998). However, in order to reach the stage of acceptance, grieving the losses was required by each and every woman. The most common theme that emerged from women's stories was that of loss. They spoke of tangible losses of body parts and bodily functions, like loss of hair and weight gain, that were so oppressive as to crowd out other considerations for a time. They were permanent physical changes like induced menopause and lymphedema. There were also intangible losses like loss of intimacy, of control, choice, trust, predictability, and a sense of wholeness. Women needed to accept the reality of the losses, before they could adjust successfully to the significant changes in their lives and build confidence again in their body image (Carter, 1993). By confronting their scars, grieving for the losses, finding ways to cope with the side effects of the treatments, using a prosthesis or having breast reconstruction, pampering themselves, taking good care of their bodies, and re-evaluating priorities, they were able to rebuild their body image.

Perhaps the most obvious concrete loss to the women in this study was the loss of their breast. It created a change in appearance, and forced them to re-examine their feminine and sexual identity. What matter even more than the physical loss was the highly personal meaning of what has been lost. Some women chose to use prosthesis to create normal appearance and help them integrate the change into their body image. Two women chose breast reconstruction, and one woman chose neither. For her, life without a breast was part of the larger commitment to realism. As she states: "I don't need to hide it and I don't want to erase it because I don't want to forget".

Because of the assumption that breast loss would leave a woman feeling "unwhole", several options have been made available to women to minimize the impact of breast surgery on physical appearance. Prior to the availability of conservative surgeries and breast reconstruction, use of external prosthetics was accepted without question in the medical literature as an essential step in the rehabilitation of women who had undergone mastectomy. This basic assumption that prostheses should be recommended continues to go untested and largely unquestioned (Meyerowitz & Hart, 1995). However, the results of the present study show that the benefits of supplying prosthetics are not always as straightforward. Certainly, some women found it useful and satisfactory, but others described it as inconvenient, and one woman found it unnecessary as she was comfortable being a one-breasted woman. These contrasting examples demonstrate the dangers of making assumptions about what all women will want.

Unlike prosthetic use, breast reconstruction, which represents another attempt to minimize psychological distress by preserving a woman's sense of wholeness, has been studied extensively in the psychological literature. Women choose reconstruction to eliminate the need for an external prosthesis and to be able to wear more attractive clothing (Schain, 1991). Other reasons for choosing reconstruction were to increase body integrity and normal appearance (Neill, Armstrong & Burnett, 1998). A substantial majority of women report being satisfied with the cosmetic results of breast reconstruction (Rowland, Holland, Chaglassian & Kinne, 1993; Schain, 1991). Some women also experience positive effects in other domains, such as body image and psychological adjustment (Mock, 1993; Pozo, Carver & Noriega, 1992; Rowland et al., 1993; Schain, 1991). While most women who choose reconstruction seem to benefit from it, they do not report better psychological adjustment, body image satisfaction, or sexual functioning compared to women who did not have breast reconstruction (Reaby & Hort, 1995; Rowland & Holland, 1998). Moreover, in comparison to women who have breast-conserving surgeries, women who undergo immediate reconstruction report worse body image and less patient satisfaction (Mock, 1993; Noguchi, Katagawa & Kinoshita, 1993). In addition, removal of tissue from the abdomen or back to reconstruct the breast leaves some patients with concerns about scarring and pain (Noguchi et al., 1993).

In the present study, two women chose to have reconstruction. The one who chose implant explained that she was choosing the least invasive and most body-preserving reconstructive method. The one who chose the TRAM-flap was avoiding the placement of a foreign object in her body and was regaining her body integrity. Both were satisfied with their decision and the cosmetic results, however, they did not describe better psychological adjustment, body image satisfaction, or sexual functioning compared to the women who chose not to have breast reconstruction. Their responses were consistent with other research findings reported above. Four women chose not to have reconstruction. Their decision contradicts the widely held assumption that every woman who looses a breast would eagerly have it replaced, and breast reconstruction is a necessary part of the treatment for and the recovery from breast cancer (Kasper, 1995). Their decision was meaningful within their experiences as women and the context of their lives.

For all participants in the study, breast cancer and its effect on their body, represented an opportunity, often the first opportunity, to confront fundamental issues of body image, and in many aspects to change it. In changing their body image, these women were also changing their world. Because having breast cancer involves such a high level of breast and body consciousness, all of these women had to confront directly how important their appearance really was in evaluating their self-worth. There is no doubt that there is a definite association between how a woman feels about her body and how she feels about herself as a person. Women traditionally have relied on their appearance and body image to bolster their self-esteem. It is what they have been taught, and most never question the societal standards of what "looks good". As a result of having breast cancer, these eight women were forced to re-evaluate conventional attitudes and standards. On balance, how they felt about themselves became a more critical factor in taking stock of their self-esteem than their appearance. As one woman summed it up: "I'm a different person now. Completely different. And very positively different. I'm stronger, my priorities changed… and I rely more on my inner strength".

Limitations of the Study

In a qualitative study, the researcher's curiosity, relationships with participants, and conceptual lenses through which data are gathered and interpreted have significant bearing on the research (Patton, 1990). This was evident in the present study. Some would criticize the subjectivity that is inherent in interpretive work, however, no research is free of the biases, assumptions, and personality of the researcher. We cannot separate self from those activities in which we are closely involved. I believe that disclosure of how one is inherently enmeshed in the research enhances the legitimacy of the findings and new insights (Osborne, 1990). Although my self was an inherent influence on the interpretive process, the meaning I brought to the data was supported by text. Moreover, the integration of existing theories, validation of my interpretation of interview data by the participants, and comparison of this research with other studies were used as strategies to enhance the interpretations (Lincoln & Guda, 1985). This is not to say that mine is the only legitimate explication of the data. As noted by Ayres and Poirier (1996), a single data set can yield multiple valid interpretations. My interpretations of the women's stories is necessarily personal and is only one interpretation of an otherwise potentially inert and meaningless text (Ayres & Poirier).

Due to the unique characteristics of the women in this study and the methodology employed, it can be argued that the themes generated from the data may not be generalized to all women with breast cancer. However, phenomenological research is not concerned with statistical generalizability. As noted by Lincoln and Guda (1985), the task of the qualitative researcher is to provide only the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether a transfer can be contemplated. Scholars who have studied various women's subcultures, such as women in childbirth, demonstrate that the experiences of individual women are often shared among women in similar circumstances. My professional experience in psychooncology lends me to believe that this transfer is indeed very possible.

In conducting the study, specific criteria were used as guidelines in participants selection. Age of the women (premenopausal) and stage of disease (no metastasis) were two of the specified eligibility criteria. It is possible that older women and /or an advanced disease might create different insights and responses to altered body image. Therefore, some of the themes that have emerged might not apply to other women with breast cancer. Similarly, participants in the study were all white, and relatively high in socioeconomic status (compared to the population as a whole), as is reflected in their education level. These limitations urge some degree of caution when generalizing the findings to other women with breast cancer.

Interviews were conducted retrospectively, and the process required that the women recall aspects of their past experience. Women reflected upon their perceptions of their bodies prior to and following their diagnosis of cancer, but these reflections and meanings are constructed from the vantage point of being one year post-treatment. It must be kept in mind that perspectives change with time and further healing, and that understanding of self and experience may change with the telling of the story. Frank (1995) asserts that the stories we tell about our lives are not necessarily those lives as they were lived, but these stories become our experience of those lives. The social scientific notion of reliability - getting the same answer to the same question at different times - does not fit here. Life moves on, stories change with that movement, and experience changes. Therefore, conducting the study at a future time may produce different stories.

Implications for future research

This study demonstrates that when we begin from women's stand-point, from women as the center of inquiry, we can begin to understand the lives of women with breast cancer, as well as the connections between individual women, the community of women, and the social order. Future studies using the discovery process of this type of methodology may reveal that the lives of women with breast cancer may be better understood with this approach.

The findings of this study also demonstrate that individual women construct personal meanings from their breast cancer experience that sustain them within the context of their lives. Different women have different opinions and concerns. Therefore, researchers should not try to simplify this complexity and diversity and assume how women will feel or what they will want. They must instead try to avoid limiting their research agenda on the basis of preconceptions about women.

More specifically, this study suggest several areas for future research. The study findings need to be validated with a more heterogeneous group of women who come from a broader spectrum of ethnic and socioeconomic groups, as well as different sexual orientation. Meyerowitz (1995) points out that a serious limitation of past research is that it has focused almost entirely on middle-class, white women. There has been speculation about the ways that culture and ethnicity might influence reactions to cancer and to typical medical interventions, yet, almost no research has tested these hypotheses systematically.

As this study was restricted by age and stage of the disease, it would be interesting to conduct qualitative studies exploring older women's perception of their body image after diagnosis for breast cancer. A comparative study of young and older women can explore if there are age-related differences in women's perception of their body image so that the impact of age on body image can be discerned more effectively (Wyatt & Friedman, 1998). Another study should further explore women's perception of their altered bodies at an advanced stage of the disease, or when the cancer recur.

Interviews in this study were conducted retrospectively, and the process required that the women recall aspects of their past experience. Prospective and longitudinal studies are required to follow-up women through diagnosis and treatment into the stage of recovery so that a trajectory of body image and breast cancer can be explored and the nature of changes over time be documented.

In the present study, four out of six women who underwent mastectomy did not choose to have breast reconstruction. Future research might further explore the reasons that keep some women from choosing reconstruction, what is the decision process involved when reconstruction is chosen, and the degree of satisfaction for the final results.

It is frequently assumed that breast cancer produces special emotional problems over and above those experienced by other cancer patients, specifically in the realm of body image and sexuality. Future research might conduct comparative studies to explore effects on body image among women diagnosed with different type of cancer.

Implications for helping professionals

The goal of this study was to provide in-depth understanding of women's perception of their altered bodies after undergoing treatment for breast cancer. It also intended to make some recommendations for helping professionals as to better help these women cope with these body image changes and integrate them into the self. Although it is not possible to generalize the findings from which these data were taken, the material does provide important insights that can enhance understanding of a problem that is experienced by many women. By incorporating the broader base of empirical knowledge into the context of clinical practice, interventions will more directly reflect the needs and concerns of women.

A large body of research describes breast cancer patients as being highly concerned about their physical appearance and their worth as women. However, the findings of this research clearly indicate that diagnosis of breast cancer does not impose one standard set of problems and responses for every woman. Some women, especially those for whom physical appearance is central to self-identity, experience intense concerns about body image and femininity and would benefit from counselling following their treatments. Most women may want to be informed of the options available for restoring external appearance, including prosthesis and reconstructive surgery. It is therefore important that health care professionals carefully assess women's needs and provide attention to their individual concerns.

The findings of this study indicate that alteration in body image with its attendant threat to the self, can persist over time, regardless of specific type of treatment. Health care providers need to be aware of the extent of the problem and the fact that it is often obscured by its highly private nature. As shared by the women in this study, the need to present oneself in a favorable light and appear well adjusted may result in care for the physical wounds while other wounds to the psyche may remain unaddressed. Problems with body image and sexual functioning are often sidestepped by both women and health care providers. A thorough and continuous assessment of the woman's response to the diagnosis and treatment may well be indicated.

Interventions with women have to be immediate, as well as long term: immediate to ease the initial response to treatments effects on their body, and long term to assist in integration of these changes into the women's life in such a way as to enable them to maintain a sense of equilibrium in the face of a devastating experience (Burns & Holmes, 1996). Ideally, an initial body image assessment of the woman with breast cancer should occur through an individual interview prior to any body image changes. That is, before the treatment has begun and before the effects of the disease process have become evident. One purpose of the assessment is to identify women who are at risk of experiencing difficulty in managing body image changes. Another purpose is to gather information that can be used to provide guidance to the woman in planning strategies to facilitate effective management of the body image changes when it occurs. During the interview it is important to assess body image factors such as: significance of present body image to the woman, physical and psychological association of the affected body parts, thoughts or feelings the woman is having about possible changed body image, and general coping skills (Burns & Holmes). Understanding the meaning and level of importance of body image to a particular woman is the first step to creating meaningful interventions. It can be achieved only by truly listening to her describe, explain and discuss what the bodily changes mean to her. Health professionals must avoid making assumptions about these women's experiences and responses to the cancer treatments. The goal is not to place the woman within our own frame of reference, one that is masked with our own beliefs and values, but to take ourselves into her frame of understanding. Embodied in her story are social and medical information that can guide caregivers. It may be helpful for the health providers to keep in mind the critical difference between the caregiver and the patient in regard to the context of the illness. The patient's experience is one of an immediate, personal, acute event with little contextual frame. The health professional has a contextual frame that includes a comprehensive vision of the course of an illness. This expertise can be used to help the patient, while giving special consideration not to minimize the empathy with the patient's immediate sense of loss.

All the women in the study experienced a profound sense of loss. They grieved and mourned not only the physical loss of body integrity, but also the loss of the intact self. To overcome, and emotionally adjust to a change in body image they had to go through a period of mourning. By facilitating the grieving process, psychologists can address the different losses women experience after undergoing treatment for breast cancer. In time, they can help women place their losses in a proper perspective so it will not hinder recovery and rehabilitation to life.

There is increasing evidence that participation in group activities offers a uniquely supportive and normalizing experience for many breast cancer patients, struggling to deal with the new realities in their lives (Rowland & Massie, 1998). Issues of body image and sexuality often emerge and shared with the other women. The findings of this study can be introduced in supportive groups to affirm both the common and unique aspects of their experiences.

Conclusions

This study of women with breast cancer produced a great deal of information about how eight women perceived their altered bodies after treatment for breast cancer, and how they learned to integrate the changes into their self-image. Their stories enhanced our understanding of body image and breast cancer. The data revealed each woman's unique and personal understanding of her body image as it was affected by the experience of breast cancer. Although their stories were unique, there do appear to be common and similar themes in their experiences. The women struggled with changes and losses which posed threats to their body image, notions of femininity, sexuality, appearance to themselves and to others, and to their sense of self-worth and even identity. Thus they were dealing not only with grief relating to loss or altered body part, but to a change of self-perception both in body image and self-image. They acknowledged that their early socialization prepared them to find their physical selves wanting as well as to view their worth through the regard of another. Their stories describe the difficult choices they made to assure their health and preserve their appearance, the battles they were forced to wage between society's expectations for women and their own best interest, and the personal insights and strengths they used to marshal their recoveries. And yet, from a seemingly uncontrollable, frightening, and life-threatening set of circumstances, they emerged with their self-image very much intact, obviously rearranged and changed, but restored.

The findings of this study have an important message for women with breast cancer at large, as well as to researchers and health care professionals. These stories can provide other women who are going through treatment for breast cancer with information that may help them to validate and normalize their own experiences. These stories also imply that there is no "woman's reaction" to breast cancer. Different women have different concerns and responses. For example, some women criticized the lack of attention to body image and disfigurement, and other women were offended by a focus on women's bodies. Researchers and care providers can not simplify this complexity and diversity, and must instead try to avoid limiting their focus on the basis of preconceptions about women.

In this study, the cancer experience created profound changes in women's lives. However, despite the many hardships they endured, all the women in the present study came away from the experience with a positive and optimistic look. Their experiences enriched them and deepened the compassion that they felt for themselves and for others. Much like the old saying that "even in the darkest clouds, there are silver linings", these women seem to have found the positive in a difficult experience. They found life richer in many ways and were energized to look for changes in the present as well as the future. The ability to move on with compassion may be the most important aspect we need to share with clients as they struggle with the breast cancer experience.

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APPENDIX A

INFORMED CONSENT FORM

Project title: Body Image as Perceived by Women Treated for Breast Cancer.

Investigator: Miri Robson, Psychologist. Phone: 432-8703 (w).

Purpose of the study: The purpose of the study is to gain knowledge and understanding of the changes in women's perception of their body image after being treated for breast cancer. Women participants in the study will be interviewed on at least one occasion, and each interview will last approximately 1.5 hours. During these interviews women participants will be asked to describe their experience with breast cancer, and how it affected their perception of their body image. It is anticipated that the information shared with the researcher will be helpful to other women in similar circumstances, as well as professionals who help these women.

This is to certify that I, ________________________________ (print name) hereby agree to participate as a volunteer in the above named study.

The study has been explained to me and I understand that:

- There will be no health risks to me resulting from participation in the study.
- Interviews will be audio-recorded and I will have an opportunity to review the transcriptions to ensure accuracy.
- All information is confidential and instead of my name appearing on any written material, a pseudonym or a code will be used.
- All audio-recordings and transcriptions will be stored in a locked office.

- The information may be published, and some of my words may be included in these reports, but my name will not be associated with the study.
- All tapes and transcribed material will be erased upon completion of the study.
- Medical information about my disease can be obtained from my medical records.
- I am free to decline to answer to specific questions during the interviews.
- I am free to withdraw my consent and terminate my participation at any time, without penalty.
- Counselling referrals will be offered if distress is experienced as a result of participation.

I have had an opportunity to ask any questions about the study, and all such questions have been answered to my satisfaction

______________________	______________________
Participant	Researcher
______________________	______________________
Witness	Date

APPENDIX B

DEMOGRAPHIC DATA

1) Pseudonym____________________

2) Date of birth___________________

3) To which ethnic or cultural group(s) do you identify yourself as belonging to?

____

4) What is the highest grade or level of education you have ever completed?

____

5) Which of the following best describes your current situation?

Working full-time_________

Working part-time_________

A homemaker___________

Retired_________________

Unemployed_____________

Student_________________

Not working due to illness________

6) If working outside the home, what kind of work did you do or are you currently doing?

____

7) What is your current marital status?

Single (never married)_____________

Married or living common law?______

Living with a partner______________

Separated_______________________

Divorced_______________________

Widowed_______________________

8) Length of marriage_____________

9) What is your current living situation?

Live with spouse/partner___________

Live with family or relatives_________

Live with friend(s)________________

Live alone_______________________

Other. Please specify_______________

10) Do you have children? (Include all children: biological, adopted, stepchildren, etc.)

If yes, how many?___________

What are their ages?_________

How many children are living with you?____________

11) When were you diagnosed with cancer?_______________________

(dd/mm/yr)

12) What type of treatment have you received?

Surgery_____________

Chemotherapy________

Radiation therapy______

Hormonal therapy (e.g. tamoxifen)______

None________________

13) What was the date you completed treatment?___________________

14) What type of breast surgery did you have?

Biopsy_____________

Lumpectomy________

Mastectomy_________

Breast reconstruction____

None_______________

15) Were any underarm nodes positive at your initial diagnosis?

No_________

Yes,________ How many?_________

Don't know___________

APPENDIX C

To participant in this study:

I am conducting a study about women's perception of their body image after being diagnosed and treated for breast cancer. How a woman views her body plays a key role in determining psychological adjustment and quality of life after treatment for breast cancer. I am interviewing women who are breast cancer survivors.

As a part of this study, you are being asked to participate in one or two interviews. In these interviews you will be asked to describe your experience with breast cancer and how it affected your perception of your body image. I anticipate that this information will be helpful to other women who are going through a similar experience, as well as to professionals who are trying to help them.

The information I obtain from you will be analyzed and written in a report. I will not use your name, or any names mentioned by you during the interview in any written material. If you are interested in participating in this study I will arrange a meeting with you to further discuss the study. Your signature on this form will provide me with permission to obtain your name and phone number from the person referring you, so I can contact you.

I____________________________________have read the above statement and agree that

____________________________________ can provide my name to Miri Robson who will contact me about the research project described above.

Signature of Participant

Participant Telephone #

Signature of Person Referring

Date

APPENDIX D

INTERVIEW GUIDE

The study is guided by the following questions:

1. Please describe what does "body image" means to you?
2. What do you think has influenced the way you think and feel about your body (i.e., events, messages from parents, peers, media)?
3. How did you feel and think about your body after the diagnosis of breast cancer?
4. How did your feelings and thoughts about your body change over the course of your recovery, since diagnosis, treatment and after?
5. What do you perceive as influences on your perception of your body (i.e., age, marital status, type of treatment, severity of illness, time since diagnosis)?
6. How did you react to the changes in your body image?
7. How did you cope with these changes? What did you do to help yourself? Did you handle it differently at different stages?
8. How do you feel about your body now?

APPENDIX E

STUDY TIME LINE

Research Title: Body Image as perceived by women treated for breast cancer.

Investigator: Miri Robson, M.Ed., C. Psych.
Counselling Psychology, Ph.D. Candidate.
Department of educational Psychology
University of Alberta.

I. Proposal Development

Sep. 1997 - May 1998	Course work in qualitative research. Reading in area of psycho-oncology, breast cancer, and body image. Development of research question and proposal.
June 1998	Candidacy exam completed.
Sep. 1998	Begin doctoral internship working with cancer patients and their families.
Oct. 1998 approval.	Educational Psychology Research and Ethics Committee

II. Participant Selection

Oct. 1998 - patients Nov. 1998	Approached family physicians working with breast cancer to inform potential volunteers about this study. Contact made with all participants to establish meeting times, expectations for the study, and consent forms.

III. Data Collection

Nov. 1998 -	Conducting interviews with participants.	
Jan. 1999	Mary	November 04, 1998
	Karen	November 13, 1998
	Holly	November 20, 1998
	Rose	November 25, 1998

Julia	December 04, 1998
Leah	December 10, 1998
Liz	December 17, 1998
Jennifer	January 10, 1999

Researcher memos and notes continued throughout the entire interview process.

Auto-tapes were transcribed by the researcher.

IV. Data Analysis

Feb. 1999 -
June 1999

Comparison of audio-tapes to transcripts.

Analysis and interpretation of each interview.
Identification of themes.

Comparison of themes among all participants.

Verification of individual and shared reflections with participants.

Second review of the literature and comparison with the findings in the study.

Discussion of findings with committee member advisor.

V. Presenting the Results

July 1999 -
Dec. 1999

Development of format of final report.

Continued review with committee member advisor.

Submission of final report.