

University of Alberta

Clothing the breast cancer survivor:  
A grounded theory of “Self”-Preservation

By

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A Thesis

In partial fulfillment of the requirements for the degree of Master of Science

In Textiles and Clothing

Department of Human Ecology

Edmonton Alberta  
Spring 2004



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*Your file* *Votre référence*  
*ISBN: 0-612-96493-0*  
*Our file* *Notre référence*  
*ISBN: 0-612-96493-0*

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## **Abstract**

The goal of this research study was to determine whether clothing and appearance were areas of concern for women who had been treated for breast cancer. Through a grounded theory approach, a story of self preservation emerged that described first the fight for preservation of life and subsequently the fight for preservation of self. During treatments, participants wanted comfortable clothing that camouflaged their asymmetry. All through the cancer experience, participants manipulated their clothing and adorned themselves to express their individuality. However, women in this study found clothing choices limited because of unexpected physical repercussions of treatment. Hidden beneath a veneer of acceptance of change, participants talked about whom they had become and their perception of societal norms regarding physical perfection. Stories of ongoing struggles with clothing comfort and with meeting an acceptable socially prescribed aesthetic demonstrate the complexities of clothing a changed body.

## **Dedication**

This thesis is dedicated to the wonderful teachers and mentors  
who worked with me so diligently on this research  
as my advisors and committee members

Professor Linda Capjack and Dr. Elizabeth Crown

and

Dr. Marilyn Hundleby

who also committed her time and expertise  
as a committee member.

## **Acknowledgement**

I could not have done any of this without the unwavering love and support of my husband, John Wooding. Thank you for always being there and always allowing me to give the time and energy that I needed to my project. You are my rock.

Also, a special thanks to my four children and their spouses. This group of gutsy kids always encouraged me to believe “that I could be anything I wanted to be when I grew up”. They gave me the strength to persevere through some trying times. Sometimes the hard choices are the best choices.

I owe a huge thank you to the special women who lent their voices and hearts to this thesis. Your willingness to share your experiences has given us new insight into quality of life for women who have experienced breast cancer. When God closes a door, somewhere he opens a window.

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## *Chapter 1 Introduction*

Approximately 19,500 women in Canada were diagnosed with breast cancer in 2001. Of those diagnosed, it was expected that after treatment 14,000 women would survive (Canadian Cancer Society, 2001). It may be expected that women, treated for breast cancer, struggle with fit, comfort, and aesthetic concerns related to clothing as they resume daily living. Surgery, chemotherapy, radiotherapy, and hormone treatments are procedures used to treat breast cancer, sometimes leaving the body noticeably changed. Treatment procedures can contribute to such physical conditions as (lymph)edema, loss of heat and sweat regulation, loss of insulation of the chest wall, reduced mobility of upper limbs and torso, skin sensitivities, and menopause. Breast reconstruction, used to regain symmetry of the torso, is an option for some women after a mastectomy and may involve incisions to the abdomen, posterior, or thighs. Even though the current trend to early detection of breast cancer contributes to less damaging surgical procedures and less invasive treatment, many survivors of breast cancer must deal with changes to the way their body looks and functions (Ganz, 1999).

During active treatment, treatment teams may provide incidental information on clothing and comfort to the breast cancer survivor (BCS) as part of the immediate adjustment to treatment effects (Ehmann, 1996). However, there seems to be little concrete and substantial information available for BCSs on ongoing clothing and comfort needs as they work through and live with the effects of treatment.

As a professional dressmaker, I was moved by the experiences of clients who were BCSs. They struggled to find clothing and fabrics that were comfortable to wear when skin conditions and body functions were altered. In an attempt to address their concerns, I was unable to uncover scholarly literature addressing the specific clothing needs of these women as they resumed their lives after active treatment. My professional experience is reflected in the words of Strauss & Corbin (1990) who suggest that if you find a situation that is less than “effective, efficient, human, or equitable” (p. 35) and there is no answer to the question, “but what if ... [BCSs struggle with clothing issues]?” there is a problem area to be explored further.

### *Assumptions*

This study of clothing issues for BCSs arose from assumptions fostered by my experiences and alluded to in the literature review. This research was based on my assumption that BCSs placed little importance on clothing comfort and appearance issues at diagnosis, yet rated their importance much higher post-treatment. I also assumed that clothing comfort and appearance for the BCS took on a different meaning as time went on after treatment.

### *Statement of Problem and Objectives*

The purpose of this research was to address the question: *What is the breast cancer survivor's post-treatment experience of clothing?*

Specifically, the objectives of the study were to:

- Identify problems and issues related to clothing experienced by the BCS after treatment and rehabilitation;
- Identify and develop clothing design criteria for the BCS, including those criteria related to clothing comfort and clothing aesthetics;
- Identify sources of information regarding important clothing criteria for the BCS; and
- Make recommendations regarding delivery of clothing related services for the BCS.

### *Justification*

From the time a woman is diagnosed with breast cancer, choices and decisions on many levels must be integrated into the process of survival. In her paper, "Choice and decision-making for women with breast cancer", Susan Leigh (1996) surmises that "the language of medicine is foreign, care providers can be intimidating and the current health care or "disease-repair" system is challenging at best" (p 144). Leigh states that a great many women are now challenging this medical model of treatment and are attempting to define survivorship and related issues from a patient's perspective.

In Human Ecology, value judgments may help address the provision of adequate and functional clothing systems for humans (Sontag & Schlater, 1995). People working in the psychosocial oncology field and BCSs themselves indicate that information on meeting clothing needs after breast cancer is not readily available. Clothing needs and assessment of appearance aesthetic concerns relating to changed needs and changed bodies have not been addressed adequately. A review of the literature on physiological concerns, psychosocial concerns, body image, and quality of life issues of BCSs includes little information on functional and aesthetic concerns related to clothing.

Findings from this study have implications across a broad spectrum of disciplines. Oncology nurses, oncologists, counseling services, support groups, textile and clothing designers, and survivors themselves will be able to integrate the findings of this study into more meaningful services for BCSs. I expect my study to form a basis of work that identifies adaptation to clothing systems as a specific concern for BCSs. Properly documented, the results of this project could enhance policy and procedures in a number of areas:

1. Improved support services that address clothing concerns in a more timely manner before problems become chronic and survivors become complacent.
2. Integration of information on long-term clothing concerns into the diagnosis process for new patients.
3. Development of wear trials that address and alleviate the problems of long-term physiological interactions of clothing and treatment effects.

Clothing a changed body after breast cancer is a component of rehabilitation that has not been explored in the context of the “lived experience” of the BCS. Recovery from breast cancer is a multi-dimensional experience and care of the survivor must include not only the medical perspective but also integration of body and interpersonal self (Bredin, 1999; Pozo-Kaderman, Kaderman & Toonkel, 1999). The medical community understands that there is a need for continued support, but such support is limited because of an apparent need to channel resources to active treatment services (Bredin). As treatment techniques emerge and evolve, continual assessment of issues and concerns are necessary to ensure that BCSs needs are acknowledged and met. It is reasonable to conclude that adequate resources and support are necessary for long-term

survivors in order for them to find strength in dealing with the difficulties caused by the cancer experience (Edgar, Remmer, Rosberger & Fornier, 2000). Recent studies affirm that more information is needed to provide a comprehensive and complete perspective on the needs of long-term cancer survivors.

### *Definitions*

For the purpose of this thesis, the following terms were used as defined below:

**Aesthetics** – an activated state of awareness of the sensual, expressive, and symbolic qualities of clothing or the experience of clothing. (adapted from Fiore, Moreno & Kimle, 1996)

**Appearance Standard** - a gauge used by individuals to create and compare their appearances to others.

**Axillary Dissection** – removal of between five and thirty axillary (underarm) lymph nodes from either below the lower edge of the pectoralis major muscle, underneath the muscle, or above the muscle. Traditionally those at the lower edge and underneath were usually removed accompanying a mastectomy. (breastcancer.org, 2003)

**Body Image** - the self-perception of one's physical body structure and function as dynamic and different from all others, taking into consideration body appearance, state of health, skills, and sexuality. (Ehmann, 1996; Cumming, Kieren & Cumming, 2000)

**Breast Cancer** malignant tumor in the glandular tissues of the breast which tend to destroy an increasing proportion of normal breast tissue over time, and may spread to other parts of the body; most common cancer in women in 2003. (Love, 2000)

**Breast Cancer Rehabilitation** - dynamic process of assisting women who are recovering from breast cancer; most effective when comprehensive, ongoing, and most effective when begun at diagnosis. (Ehmann, 1996)

**Breast Cancer Survivor (BCS)** – a person who has been diagnosed with breast cancer, has been treated, and, after treatment, is alive and remains disease free. The disease is not exclusive to women, as men may also be diagnosed with breast cancer.

**Breast Conserving Treatment (Lumpectomy)** – the most common form of breast cancer surgery today, encompasses removal of breast tumor, a margin of surrounding healthy tissues and in most cases, includes an axillary dissection. (Baron, Kelvin, Bookbinder, Cramer, Borgen, & Thaler, 2000)

**Chemotherapy** - most often refers to cancer treatment, where powerful drugs with potentially severe side effects are used to eliminate or contain the spread of tumors and to treat the cancer. (Love, 2000)

**Comfort** - a feeling of well-being, a pleasant state of physiological, psychological, and physical harmony between a human being and the environment. (Slater, 1986; Hatch, 1993)

**Fibrous tissue** - The term usually refers to tissue laid down at a wound site which was well supplied by blood vessels (granulation tissue) but later is without blood or lymphatic vessels and dominated by collagen rich extracellular matrix, forming a scar. Excessive contraction and hyperplasia leads to formation of a sharply elevated, irregularly shaped, progressively enlarging scar. (CancerWEB)

**Functionality** – an instrumental or functional quality or condition, exhibiting normal action, use, or purpose.

**Lymphedema** –incurable consequence of axillary node surgery (removal) and radiation (Brennan & Miller, 1998). Abnormal accumulation of tissue proteins, edema, and chronic inflammation within an extremity. (Brennan, DePompolo, & Garden, 1996)

**Macro Environment** – setting or atmosphere which includes an environment of a given culture or subculture, including the belief systems, bodies of knowledge, material resources, customs, life-styles, opportunity structures, hazards and life course options associated with those environments. (Bronfenbrenner, 1994)

**Mastectomy** - surgical removal of all or part of a woman's breast when cancer has been detected. (CancerWEB)

- Modified Radical Mastectomy – removal of breast, nipple, and lymph nodes (glands) in the armpit and associated skin and subcutaneous tissue. It differs from total radical mastectomy in that the chest (pectoral) muscles are preserved.
- Radical Mastectomy (Halsted procedure) – removal of the breast, pectoral muscles, axillary lymph nodes, and associated skin and subcutaneous tissue.
- Total Mastectomy –the affected breast is removed along with the nipple and underlying muscle.

**Medical Model** - A set of assumptions that views behavioural abnormalities in the same framework as physical disease or abnormalities. (05 Mar 2000) (CancerWEB)

**Micro Environment** – setting or atmosphere directly surrounding an individual affected by patterns of activities, social roles and interpersonal relations in a face-to-face interaction with specific physical, social, and symbolic features. Proximal processes operate in this environment to produce and sustain individual development. (Bronfenbrenner, 1994).

**Radiotherapy (Radiation therapy)** – a localized treatment where photons are beamed directly at a body part directing 4500-5000 rads to the area (in comparison a chest x-ray is a fraction of a rad). (Love, 2000)

**Sentinel Node Biopsy** – removal and examination of the first node in the axillary chain of lymph nodes. If this node is clear of cancer, the nodes further down the chain are left undisturbed. (von Smitten, 2000)

**Somatic** - relating to the body and its functioning (Wyatt & Friedman, 1996). Pertaining to the body wall in contrast to the viscera. (CancerWEB)

## *Chapter II Literature Review*

Much is written about clothing, yet little interpretation has been made regarding the importance of clothing or appearance aesthetics to a person's social identity when changed by serious illness. A literature review on breast cancer and other related areas of interest provides little information on how the BCS feels about clothing her changed body. There is no information on how she adjusts her clothing choices to accommodate the effects of treatment.

The literature review is organized into six main sections: quality of life, physiological concerns, psychosocial concerns, body image, clothing, and recommended research methods. Section one reviews literature on quality of life after treatment for cancer and includes a discussion on support for survivors. Section two gives an overview of the treatments for breast cancer and the ensuing somatic concerns. Psychosocial implications of breast cancer and its treatments are then reviewed in section three, along with self-transformation and self-preservation, coping, and decision making. Section four covers the topic of body image, and discusses femininity and body integrity after breast cancer. Symbolic interaction and post-treatment self-concept are also discussed. Section five reviews literature on clothing that incorporates concepts of physical, psychological, and social comfort, as well as appearance aesthetics. Section six gives an overview of research methods used and suggested by others involved in studies of cancer, breast cancer, and its effects.

Following a review of the literature, an overview of the conceptual model used for this study shows the relationships between clothing, the requisite social and physical components of clothing comfort, the BCS, and her micro and macro environments. This model visually demonstrates the interaction between the physiological and psychological attributes of a human being, who in turn presents a personal image to the external world through the symbolism of clothing.

### *Quality of life after breast cancer treatment*

Having breast cancer may not be the worst thing that can happen to a woman and in fact, it may be the lengthy process of treatment, survival, and rehabilitation that presents the significant challenge. Women and their families face many non-medical challenges after a diagnosis of breast cancer that affect quality of life. Phases of adaptation to cancer in the medical model are identified as acute, chronic, and resolution, with each phase presenting different demands on the patient and their support network (Lederberg, 1998). The acute phase encompasses diagnosis and primary treatment, along with complications that may arise because of treatments. The chronic phase generally involves the recuperation period after primary treatment and includes adjuvant therapies. It can be described as a time when a person is most fearful of recurrence. The resolution phase involves recovery and adaptation to a changed body, or an acceptance and accommodation that death may be imminent. The demands which confront the patient and her support network in the course of diagnosis, treatment, and recovery vary from one illness stage to another (Heim, Valach & Schaffner, 1997).

Research on quality of life for long-term BCSs is missing and in spite of the amount of research on breast cancer, factors that aggravate and relieve physical discomfort have not been well studied (Baron, et al., 2000). Even though appearance related concerns are sometimes ranked as more severe than somatic side effects after treatment, there is not complete agreement on what constitutes the specific dimension of quality of life for BCSs (White, 2000; Bredin, 1999). In a study with 188 long-term female cancer survivors conducted by Wyatt & Friedman (1996), physical concerns or the absence of somatic concerns relating to the body and its functioning (physiology) was rated highest for a quality of life issue. There is also some evidence that BCSs may be conditioned early in the clinical process to show their gratitude for surviving by hiding their discomforts (Bredin).

Most patients are supported by the medical community through the difficult stages of diagnosis, treatment, and the initial post-treatment period when adjuvant therapy may be administered. In Ehmann's (1996) study, fourteen nurses working with mastectomy patients during this critical time were surveyed for their thoughts on



effectiveness of post-operative treatment. Thirty-eight per-cent of nurses thought women were satisfied with their prosthesis. Fewer than 20% were familiar with products available, and 86% were not able to identify prosthesis costs for women. Fifty-seven per-cent did not know when a women should start wearing a prosthesis (Ehmann).

In the same study, of the 28 mastectomy patients surveyed, 88% indicated they delayed returning to the workplace because of an asymmetrical appearance; 85% were unaware of product options for prostheses; 41% wanted pre-mastectomy education and counseling about image restoration; and 23% wanted immediate post-operative education (Ehmann, 1996). This study indicates that medical staff most intimately involved with BCSs are not aware of the true post-treatment information requirements of the patients. It would be helpful to know, eight years later, if this gap continues to be an issue for more recently treated BCSs.

Access to activities and resources is part of the social support that is required during times of profound stress and change. Post-treatment, the disease may be gone, yet patient anxiety levels rise as they lose contact with health care professionals, but continue to experience side effects. The experience of loss is profound and ultimate fear of recurrence makes this a vulnerable time for those leaving the clinical setting (Pozo-Kaderman, et al., 1999; Crooks, 2001; Edgar, et al., 2000). It is generally believed that post-treatment support for non-medical concerns is imperative to patients' optimal healing adaptation.

More often, women are given information on services relating to recovery and recuperation from breast cancer and are expected to access these services on their own. Through a survey of women completing treatment for breast cancer, Edgar et al., (2000) found that 40 – 60% of respondents learned about resources available to them through their own initiatives. Resources in this instance were defined as sources of support or strength that helped women deal with difficulties caused by the experience of cancer. Carpenter, Brockopp, & Andrykowski (1999) report in their study of 60 BCSs that the women described a lack of information and support from health care providers, friends, and family. They also lacked resources, such as finances, physical stamina, time, and supportive relationships that allowed them the opportunity to search out the support they

needed. These women were between three months post-diagnosis and 54 months post-treatment.

### *Physiological Concerns Related to Treatments*

All medical treatments for breast cancer revolve around some form of surgery, radiotherapy treatment, chemotherapy, and/or hormone therapy. Treatments such as surgery, lymph node dissection, and radiation that ensure long term survival are sometimes the most invasive and debilitating. Muraoka and Gotay (1998) and Meric, et al. (2002) found that long term survivors continue to experience negative effects of cancer well beyond completion of treatment regimens. Somehow, survivors learn to live with or adjust to their limitations over the long term, and endurance was commonly voiced by participants in those two studies.

In Brennan et al.'s (1996) study, respondents between the ages of 40 - 55 had a lower quality of life sub-scale regarding somatic concerns. Those with the longest survival times indicated lower quality of life overall. Even though Wyatt & Friedman (1996) suggested that the physical domain remains only a residual issue to long-term survivor's quality of life, the authors, along with Crooks (2001) suggested that issues relating to somatic concerns should be addressed earlier in the recovery process, before compromise and endurance set in.

### *Effects of Surgery*

In the past, surgery has been the primary treatment for most breast cancers and with this treatment there can be post-operative sensations involving the axilla (underarm area), breast, and/or chest wall (von Smitten, 2000; Baron et.al., 2000). Numbness, tenderness, pulling, soreness, and tightness were the most prevalent sensations outlined in Baron's study. There also may be muscle atrophy, weakness, and decreased range of motion. Warmuth, et al. (1998) indicated that 55% of women studied exhibited at least one of the aforementioned symptoms two to five years after surgery, even though severe complications or symptoms that had a major impact on daily activities were uncommon.

Smith, Bourne, Squair, Phillips, & Chambers (1999) estimate that 43% of women who undergo mastectomy suffer from post mastectomy pain syndrome (PMPS). PMPS is defined as neuropathic pain that is characterized by numbness, pins and needles, and burning or stabbing sensations in the axilla, arm, shoulder, or chest wall on the side of the surgery. Smith et al. also noted that many women did not report their symptoms prior to the study because they felt it was something they would have to tolerate as a consequence of surviving breast cancer. The authors concluded that PMPS is aggravated by straining, sudden movements, tiredness, clothes rubbing, cold weather, and coughing. The reference to “clothes rubbing” is one of the few found in the literature review.

The principal cause of PMPS has only recently been connected to the trauma to the intercostal brachial nerve, which is breached within the wall of the chest during surgery (Randal, 2000; Smith, et al., 1999). When that discovery was made, the condition was classified as neuropathic pain and a complication of breast surgery. Before this connection was made, many women were thought to be neurotic and to be imagining the discomfort (Smith et al.). This point is corroborated by Crooks (2001), who found that older women’s feelings surrounding other aspects of their breast cancer experiences were considered abnormal, weakly feminine, and over-sensationalized.

Approximately 40% of post mastectomy patients experience neuropathic pain of varying severity at some point in time (Smith, et al., 1999). Reasons for frequency of the condition remain uncertain and may be revealed by further in-depth, qualitative studies. There seem to be significant differences in painful sensations for patients depending on age and handedness. Studies show that the younger the patient, the worse the symptoms (Baron, et al., 2000). This finding, coupled with Crooks (2001) discovery that older women are sometimes given more invasive treatment, has implications across a much wider age range.

Axillary dissection, which is the removal of lymph nodes under the arm nearest to the cancerous breast, contributes to higher levels of sensation or loss of sensation. As sensations became more apparent, so did distress. Baron et al. (2000) found that sensations significantly interfered with a patient's activities in daily living. The BCSs experience is exacerbated by surgical scars, pain, skin sensations, skin numbness, and muscular tension after mastectomy. In Bredin’s (1999) study, women identified

sensitivity of skin around scar sites and sensitivity to changes in chest shape. The more physical compromise experienced, the more psychological distress displayed by a patient.

### *Effects of Chemotherapy*

Chemotherapy, one of the most powerful weapons against cancer, is a systemic therapy that affects the whole body and not just one local area. Different drugs may be used and each is chosen individually depending on a patient's type of cancer. Some chemotherapy regimens are administered prior to surgery to shrink the tumor, but most are delivered post surgery to kill any lingering cancer cells in the body. Because cancer cells divide at a much faster rate than normal cells, they are affected most by chemotherapy. Each cycle destroys more and more cancer cells without wiping out the entire immune system (Love, 2000). Chemotherapy reduces the recurrence of cancer by about a third and seems to be least effective for women over the age of 50. Women who have no lymph node involvement only derive a slight benefit from this form of treatment (Love).

Even though there are many side effects of chemotherapy, women are affected differently, and not all side effects occur in all people. Side effects may include nausea and vomiting, appetite loss, menopause and resulting infertility, hair thinning or total hair loss, fatigue, weight gain (even with appetite loss), bone loss, and heart disease. There may also be mouth sores, headaches, and severe burning to the skin from chemotherapy drugs, such as Adriamycin<sup>®</sup>, leaking from the vein. Chronic bone marrow suppression, decreased cognitive function (chemo brain), and second cancers, especially leukemias, are long term side effects associated with chemotherapy treatments (Love, 2000).

Taxotere<sup>®</sup>, an aggressive chemotherapy drug, has recently become the standard chemotherapy treatment for breast cancer patients. The most common non-severe side effects include nausea, hair loss, and permanent hair thinning. In general, common side effects reported for Taxotere<sup>®</sup> are reduction in white and red blood cell counts and infection. Other common side effects are joint and muscle pain, and nerve pain. Severe hypersensitivity may also occur in the form of shortness of breath, low blood pressure, and skin rash. The likelihood of adverse side effects is lowered by several types of medications that are given before the infusion (Mesothelioma Cancer Treatment Center).

### ***Effects of Radiotherapy***

Radiotherapy (radiation treatment) is a localized treatment aimed at a specific area in the breast. It is usually used with lumpectomy and in conjunction with mastectomy for those most at risk of recurrence i.e. those with over four positive nodes, lymphatic vascular invasion, or a large tumor (Love, 2000). Radiation is applied to the immediate area of surgery usually after the completion of chemotherapy treatments.

Each woman reacts differently to radiation treatments. Some experience mild “sunburn” and some women have severe burning. Radiation may affect the lungs, resulting in a cough. Women report feeling tired. Radiated breasts sometimes swell and become more sensitive. Skin may feel thicker after radiation and may be discolored. Radiation is known to increase the effects of lymphedema and also contributes to numbness in the arm and hand. Inflammation between the ribs and breastbone connective tissue may also develop and resulting pain develops in the chest area that is arthritic in nature (Love, 2000). Warmuth et al. (1998) reported that radiation therapy was associated with a higher frequency of infections or inflammations in the arm and/or breast than had previously been documented.

One of the acute side effects of radiation therapy to the breast is skin reactions (O'Rourke & Robinson, 1996). Even with the less severe radiation methods used today, many BCSs continue to experience after-effects that can include erythema, increased pigmentation, folliculitis with pruritus, hair loss in the treated area, dry desquamation (peeling), and moist desquamation. Although these reactions vary from patient to patient, O'Rourke & Robinson state that to the date of their paper, many skin care regimens for patients receiving breast irradiation were non-research based.

### ***Effects of Hormone Therapy***

Hormonal therapies are commonly given to women with estrogen positive tumors. Tamoxifen<sup>®</sup> is one of the better known hormone therapies used after a diagnosis of breast cancer. You simply take a pill daily for an extended period of time. Hot flashes are a common side effect of Tamoxifen<sup>®</sup> and occur for about 50% of women taking the drug. Other side effects are blood clots, pulmonary emboli, visual problems, depression, nausea

and vomiting, and vaginal discharge. The most serious side effect is incidences of uterine cancer in women who are both overweight and who had hormone replacement therapy prior to contracting breast cancer. Positive effects of Tamoxifen<sup>®</sup> are that it decreases the chances of getting cancer in the remaining breast and improves your HDL and LDL ratios, thereby lowering your risk of heart disease. At this time Tamoxifen<sup>®</sup> treatments are only administered for a five year period (Love, 2000).

### *Lymphedema*

Lymphedema (edema) continues to be the most troublesome and feared consequence of breast cancer surgery and radiation treatment. Sixty percent of survivors of radical mastectomy experience this condition, which can occur after radical and partial mastectomy, axillary node dissection, or injury to the arm. It is more prevalent in women who receive radiation to the axillary area (Ganz, 1999; von Smitten, 2000).

Lymphedema is characterized by an abnormal accumulation of interstitial fluid, tissue proteins, edema, and chronic inflammation within an extremity (Ganz). After the lymph nodes have been removed or altered by radiation therapy, the arm on the side of the treated breast can be swollen and painful. This causes extreme discomfort, necessitating the wearing of garments that are non-constricting. There may be limited movement, and an increased risk of infection. Lymphedema may cause serious disfigurement, pain, unsatisfactory cosmesis, loss of extremity functionality, and psychological and social issues. The affected arm can be difficult to fit with clothing, and along with pain and loss of motion, can lead to emotional distress and social barriers (Ganz; Brennan & Miller, 1998). Adequate coverage of the swollen arm is particularly important to avoid incidental skin trauma such as minor burns, abrasions, and lacerations. These injuries may lead to infections exacerbated by the dysfunction of the lymph system (Brennan, et al., 1996).

Meric, et al (2002) state breast-conservation surgery and radiotherapy are becoming the standard of care for early stage breast cancer patients. After studying long-term complications associated with this regime, the authors noted that although only 10% of participants in the study experienced arm edema within 3 years of treatment, this figure increased to 30% at the 10 year mark. This indicates arm edema will have

significant impact on the quality of life for the long-term BCS. The literature on lymphedema demonstrates the gap of knowledge about clothing the arm in an appropriate manner.

### *Psychosocial Concerns*

There is increasing recognition that issues other than those viewed as strictly medical are important to consider within the context of standard care for breast cancer patients. There are many non-medical changes that accompany the process of diagnosis of, treatment for, and recovery from breast cancer (Pozo-Kaderman, et al., 1999). The new image of self and body suggests that some sort of transformational process has to take place.

### *Self-Transformation & Self-Preservation*

As a person deals with a life-threatening illness such as breast cancer, changes in attitude, perspective, meaning, outlook, and interpersonal interactions take place as the self is "transformed" by this experience (Carpenter, et al., 1999). Research on factors associated with individual differences may identify social constraints that block the ability to make effective changes in these five areas after cancer diagnosis. Social constraints refer to social conditions that make individuals feel unsupported, misunderstood, or alienated when seeking support (Carpenter, et al.). The authors state that researchers have not adequately explored self-transformation and how positive changes associated with this process may have a positive impact on wellbeing and healing.

A grounded theory study by Thomas and Retsas (1999) described the process of "transacting self-preservation" in relation to spirituality for terminal cancer patients. Thomas and Retsas identified the phases of "taking it all in", "getting on with things", and "putting it all together". The authors talk about patients' search for meaning in the cancer experience and the need for finding some way to "preserve themselves" as they moved through terminal illness. They found that in the cancer recovery process there was a deeper level of understanding of self and an incorporation of higher levels of all

things spiritual (Thomas & Retsas). Although the authors spoke of transformation, they did so in conjunction with other descriptors that were incorporated into the process of self-preservation.

Associated with self-preservation is a strong survival instinct. Survival is a very focused period when energy is quickly directed to overcoming threats to existence (Siebert, 1996). After a period of adjustment, people whose survival is in question, look hard and imaginatively at how to solve their problems. They recognize that their situation is temporary and that they have some control over finding solutions to their problems.

Siebert (1996) feels that transformation is a component of self-preservation. Prior to a life altering experience, an individual may live their life as a “noun” – someone who is a good mother, a good wife, a model citizen, or an exemplary employee or manager. The strength gained from extremely distressing experiences moves the person to live according to inner judgment rather than a socially imposed role. Successful coping and making a “good” adjustment to a diagnosis of cancer means that to survive, one must demonstrate the qualities that best exemplify self-preservation. Development of a unique combination of strengths and capabilities is necessary in order to comprehend and deal with the new reality (Siebert). These strengths and capabilities come from who you are as an individual and not who you are as a “noun”.

Three ways to cope in tough situations are to leave the situation, change the situation, or change your attitude. True survivors know which option, in which amount, is appropriate to get them through (Jenkins, 2003). Breast cancer patients do not have the option of leaving the situation, unless they choose not to be treated and subsequent death. Changing the situation might include choosing alternative therapies instead of standard medical treatment regimens, or by taking more time than normal to fully comprehend the options available. This may be the point, after diagnosis, where patients become more proactive about how their treatments will progress. When diagnosed with cancer, a change in attitude would be perceived as the most logical option for someone. The realization and activation of qualities and characteristics, never before realized in ones self, has a profound impact on an individual.



### *Coping and Decision Making*

The process of coping is seen as a transactional process of adaptation varying with the diverse and specific requirements of each patient (Heim, et al., 1997). Livneh (2000) reviewed literature on the role of coping styles and strategies in psychosocial adaptation to cancer. He suggests that problem-focusing or engagement-orientation by a patient is predominately associated with better psychosocial indices of adaptation. Carver and Harris (2000) found that patients, experiencing little control over the outcome of their disease, could still initiate positive outcomes by turning their efforts towards other things where they did have control, such as daily activities or emotions. The authors identified personal control, or self-efficacy, as important in dealing with stressors. Cancer patients who have an internal locus of control take a more active role in actions that affect their lives. Persons who believe others determine outcomes for them, often referred to as having an external locus of control, are less likely to be proactive if they perceive their actions will be futile (Carver & Harris). Patients who receive educational interventions, who are taught coping skills and how to effectively address emotional concerns, fare better than those who do not receive such services (Pozo-Kaderman, et al., 1999). All participants in Bredin's (1999) study indicated that they could cope if they kept up appearances and concealed their differences.

Women feel it is imperative that their health care professionals discuss everything that is important with them and that they take time to ask about a patient's thoughts and feelings on all aspects of breast cancer (Rustoen & Begnum, 2000; Rankin, Newell, Sanson-Fisher & Girgis, 2000). Women want to know that all long term implications have been discussed with them and that implications for the quality of life and short, medium and long term benefits and risk have also been addressed (Williamson, 1996). Kraus (1999) found that even though women were involved in treatment decisions, such decisions were based on chances of survival. After treatment, they were distressed with a changed body image, even though they were satisfied with their perceived participation in important treatment decisions (Kraus). Crooks (2001) found that women seldom had needs addressed when they fell outside the physical treatment situation.

### *Body Image*

In spite of the devastating effects to body function and integrity after treatment for cancer, those working in psychosocial oncology have difficulty in clearly defining the term body image (White, 2000). If a woman's body image includes a feeling of what she thinks she looks like, her wholeness and integrity of form, and if clothing is considered a significant component of outer appearance, then clothing issues for BCSs need to be explored. Rudd & Lennon (2001) state that "body image is a personal characteristic that impacts our appearance management behaviours, feelings of worth, shopping practices, and social interactions" (p.129) and suggest that body image is logically related to aesthetics and the social psychology of dress because of the perceptual and affective components of body image. The bodily self comprises a combination of body sensations, functioning, and image, and plays an important role in the presentation of appearance. Bredin (1999) suggests that women often feel that they have a new identity after breast cancer and often conceal the problems they experience when living and dealing with a changed image.

There are few evidence-based interventions available for BCSs in addressing the problem of altered body image. Healthcare professionals do not appear to know how to help women cope with the changes and, in fact, it may not be initially apparent to them that there is a problem (Bredin, 1999; Ehmann, 1996). Even though the women in Bredin's study expressed loss at "every level of their being", the grieving of this loss is part of the natural healing process and is reported to diminish in importance as rehabilitation continues and self-acceptance is realized (Bredin). Younger women appear to be more distressed about their physical appearance after a mastectomy and the limitations of prosthesis use (Roberts, Livingston, White & Gibbs, 2003). A number of researchers have found that survivors of mastectomy hide the distress of their loss because of the fear of stigma in a culture that places so much value on a woman having a perfect body and blemish-free appearance (Bredin; Lennon, Rudd, Sloan & Kim, 1999). If researchers have been misinterpreting women's perception of body image, there are implications for redefining the context for those most at risk for poor adaptation to surgery and treatment procedures.

## *Femininity*

With the advent of new surgical procedures such as lumpectomy and advances in breast reconstruction, there has been a societal focus on physical perfection after diagnosis of breast cancer (Cumming, et al., 2000). Gender coding and body mapping may be strategies employed by BCSs as they deal with a changed body and come to a deeper understanding of what constitutes their femininity (Henderson & DeLong, 2000). Gender coding involves displacing cues from the body onto the dress and is a visual representation of gender choice. This concept has also been referred to as “decentreing” and is defined as to “devalue what has previously been central, to call attention to what has been ignored, and to force reconsideration to the place and significance of previously marginalized elements” (Henderson & DeLong, p.246). Loosely fitting or diverse clothing options have the capability of diverting attention from the female form.

Gender coding, or decentreing, is employed by a woman who chooses asymmetry over attainment of the feminine silhouette after a single mastectomy. Her message is that observers value her first as a human being and do not judge her by her physical attributes. There is no clear indication from the literature review how prevalent the choice of asymmetry is for women who have lost a breast to cancer. The use of body mapping takes place when parts of the body are unexpectedly exposed (Henderson & DeLong, 2000). There is a suggestion that individuals who use this strategy displace the focus of attention from the rounded edges of the female body shape to more of a clothes-viewing priority.

Related to femininity is the concept of sexuality. In Wilmoth’s (2001) study, the core concept of her grounded theory of BCSs was found to be an “altered sexual self”. Wilmoth makes significant mention of clothing in this study as she explored women’s feelings of “missing parts” and their ability to have their illness become invisible under clothing. In the past, a quantitative and masculine perspective of frequency of sexual activity and intercourse was used as a measure of a healthy concept of sexuality and was the primary focus of sexual adjustment after diagnosis of breast cancer. The author surmised from her study that BCSs define sexuality more as comfort with self and body, and whether or not they felt attractive, fat, or old (Wilmoth).

Because chemotherapy can bring on chemically induced menopause, this usually normal phase in a woman's reproductive life now occurs suddenly, unexpectedly, and in tandem with the loss of, or change to, the definition of the breast(s). A majority of women involved in a study of menopausal stages and body image indicated that personal features they were most satisfied with were height, hair, facial features, and their upper torso (Deeks & McCabe, 2001). For women thrust into menopause unnaturally by chemotherapy, two of these features figure prominently during their breast cancer rehabilitation period – loss of hair and loss of torso integrity. Menopause and breast cancer do not appear to have been studied together in relation to a woman's changed body image. As implied throughout the literature review, new treatment interventions produce new side effects that impact a woman's long term options in more profound ways.

Wilmoth (2001) found that chemical menopause had an effect on how women perceived themselves and the feeling that the "loss of bleeding" signified they were becoming old and, along with the breast, had lost another component of their womanhood. Deeks and McCabe (2001) found that women who were menopausal had lower self-ratings on measures related to attractiveness. Older women, as a rule, are generally more dissatisfied with their bodies than younger women. Therefore if older women are most commonly confronted with a breast cancer diagnosis and they already perceive that they are less attractive, a woman's age, combined with chemically induced menopause and breast surgery, provides an ideal climate for serious body image disorder.

In a study conducted by Howell and Beth (2002), women between the ages of 40 and 60 took part in focus group discussions on women's midlife myths and realities. Even though the women involved in the study were classified as in mid-life, they generally spoke of other middle-aged women as "they" and used negative descriptors such as "overweight", "dumpy", "matronly", and "tired". When the women in Howell & Beth's study spoke of themselves, they referred to themselves as "I" or "we" and they tended to use more positive terminology, such as "gorgeous", "role model", "smarter" and more intuitive when referring to themselves.

Many women in the mid-life phase experience loss(es) related to relationships, bodies, and finances (Howell & Beth, 2002). Although relationship changes were

considered the most powerful mid-life realities, shifts in health and appearance make them most visibly identifiable as middle-aged. Yet through these changes, the women stated that this was an avenue of exploration that helped clarify what was important to them and allowed the necessary adjustments to mid-life changes to be made (Howell & Beth). The changes in their bodies brought them to a realization that their lives were half over and made them more aware of their mortality. This relates back to self-transformation and personal awareness. Some BCSs, who find themselves in lower socio-economic strata, experience decreased financial stability through the cancer experience, again compounding the effects of the changes to body and health.

### ***Body Integrity***

Carver, et al.'s (1998) study revealed that body image not only is related to physical appearance, but also is a perception of body integrity, wholeness and normal functioning. Body integrity relates to specific appearance concerns that may involve the loss of a body part, scarring, disfigurement, adjustment to a prosthesis, or limited functional abilities. There can be hair loss, nausea, fatigue, and weight gain during chemotherapy, skin discoloration from radiotherapy, and disfigurement and loss of functionality after breast cancer (White, 2000).

One of the most important conclusions from Carver et al.'s study (1998) was that an investment in appearance prior to contracting breast cancer made women more resilient to deterioration in their perceptions of attractiveness. Findings ran counter to what the researchers had been expecting, as it had been assumed that women who were highly invested in appearance might suffer more psychological distress at physical change. Even though these women did exhibit more distress pre-surgery and for the first year, they had less disruption to their sense of femininity and sexual desirability over time. They seemed to feel that they were in control of the outcome of their appearance (Carver, et al.). Surprisingly, women who exhibited a low concern about appearance from the beginning, drifted downward in their perceptions of their attractiveness.

### ***Symbolic Interaction & post treatment self-concept***

Symbolic interaction is an important component of grounded theory methodology and should be considered in any study of self-concept where we expect the self to emerge from interaction of the person with their social environment (Carpenter & Streubert, 1999). Symbolic interaction is defined as derived meaning from social interaction between and among individuals. As purposive agents, humans interpret their worlds, rather than simply reacting to a set of stimuli. The meanings derived from this interpretation guide and form individual action (Schwandt, 1997). Because humans communicate through language and other symbolism, significant symbols of communication, such as those found in clothing, are created to relay meaning.

Self-concept and symbolic interaction are tied together in *social identity theory*, which explains why people separate into groups and identify with other group members in a more positive light (Lennon, et al., 1999). This theory suggests that personal and social identity arise from inclusion in a group, and an individual's identity with the group is tied to appearance. Lennon, et al. suggest that connecting body image and social identity might be helpful in the study of social comparison, collective self-esteem, and appearance-management behaviours. Socially constructed identities are acquired on the basis of the social positions individuals fill and these identities are associated with implied social roles (Roach-Higgins & Eicher, 1992). Identity is a composite communicated by dress, bodily aspects of appearance, and material objects. Humans are not restricted to one identity. They may use all or each of their identities to connect or distance themselves from others.

Since the 1960's, the symbolism of appearance has been linked to identity formation and symbolic interaction (Roach-Higgins & Eicher, 1992). When the symbolic image of a garment and an individual's self-concept agree, there is a positive evaluation of the garment (Davis, 1984). The research proposed here may show that if self-concept remains intact after treatment for breast cancer, the BCS has a greater feeling of being attractively clothed when wearing garments she likes and feels are aesthetically pleasing. It may be found that post-treatment clothes, worn solely for comfort considerations, might reduce positive feeling of self if those garments were considered unacceptable or unappealing in the pre-cancer condition.

Roach-Higgins & Eicher (1992) suggest that personal experiences enable individuals to predict in advance what sort of a reaction their form of dress will precipitate. If the reaction coincides with the prediction, a satisfactory social interaction takes place and there is a validation of self (Roach-Higgins & Eicher). Therefore, dress is a factor in identity development as well as the development of a sense of self. I suggest that the media and market presentation of a perfect, symmetrical female body predetermines for a woman how others will react if this image is not presented. A trade magazine from 1915 extolled the use of brassieres by women to “retain the natural lines of youth and support sagging muscles” (Farrell-Beck, Poresky, Paff, & Moon, 1998). This statement supports the fact that even as fashion has changed over the last hundred years to meet body modification health concerns, in the early 1900’s a youthful, well-toned appearance was and continues to be a prime consideration in marketing to women.

BCSs experiences cannot be isolated from social relationships, as their experiences inform their decisions on multiple levels. The subsequent reasoning arises from the symbolic interactions between the individual and related environments. The perception of “self” is seen as a process rather than a thing. Our perceptions of our appearances are largely based on how others see us. In relation to the process of how others analyze our appearance, Kaiser (1997) outlined the three stages of the alternate process - our perceptions of how others see us. We imagine what we look like to others; we imagine others’ perception of our appearance; and self-feeling emerges from these thoughts. Kaiser found that women define themselves in terms of appearance more than do males. Do we choose our clothing based on purely personal, intrinsic criteria, or are our choices based on the roles we play in society and the image we are expected to portray to the external world?

We know that BCSs are encouraged to be “invisible” by returning to “normal” as quickly as possible after treatment. Henderson and DeLong (2000) describe the desire to appear “normal” as a resistance to categorization. Although headwear is worn to retain heat, there is also the perception by BCSs that wearing hats will hide the treatment effect of hair loss and make them less identifiable as a cancer patient. Makeup helps camouflage the ravages of disease and also the effects of treatments. Prostheses can provide equalization of weight to the body after a single mastectomy, but also hide the

fact that breasts, symbols of femininity, have been lost. The first symmetry-improving mastectomy brassiere was developed as early as 1930's by Gabrielle Poix Yerkes (Farrell-Beck, et al., 1998).

British sociologist Carol Thomas, in her personal narrative as a woman with a disability, is quoted by Lamb (2001) as saying:

“I still struggle with the ‘reveal or not to reveal’ dilemma, and more often than not will hide my ‘hand’ and ‘pass’ as normal. But concealment carried, and continues to carry, considerable psychological and emotional costs and has real social consequences. . . . I remember standing in front of a full-length mirror gazing at myself with the latest cosmetic hand on – how strange and unnatural it looked. . . . However they did their work indirectly because the underlying message was clear. The experts were saying that my ‘hand’ was something to be hidden, disguised. I had to appear as ‘normal’ as possible. I found the easiest solution was to hide my ‘hand’ in a pocket, and I became very skilled at this concealment. Thereafter I always had to have clothes with a strategically placed pocket.” (p. 139-140)

Non-technical literature and personal communication with BCSs has also brought up the importance that the BCS “look normal” and how important it seemed to everyone around them that they find a way to hide the aftermath of the disease (Friedeberger, 1996; Ehrenreich, 2002). Although BCSs do not necessarily have a disability, Lamb encourages society to make the reality of the disabled a social construct rather than an individualized, medical problem or, in the case of Carol Thomas, a problem to be made invisible. Ehmann (1996) found that addressing change could be therapeutic and recuperative if BCSs were encouraged to take control of meeting new aesthetic needs. Appearance change and its importance to patients must be understood in order to facilitate adjustment on a psychological level.

### *Clothing*

Clothes play a major role in appearance and a major role in our relationships with others. Because clothes serve multiple purposes, it is important to acknowledge multiple motives and needs and the varying importance of such needs (Kaiser, 1997). Kaiser states that few studies today focus on motives in everyday dressing, even though we



understand the complexities involved in clothing choices, such as components of physical, psychological, and social comfort. Changes due to treatment for breast cancer cause alteration in human system processes and therefore may change the process used to evaluate clothing. Physical comfort issues may increase as clothes interact differently with a changed body. Psychological and social comfort may be affected when a woman has an altered outer image, as well as an altered internal feeling about her body. Traditional theories that explain clothing behaviour come primarily from the disciplines of psychology, sociology, and social psychology (Davis, 1984; Rudd & Lennon, 2001). *Comfort theory* and *aesthetics theory*, which are considered social-psychological theories, more directly explain some of the clothing choices made by BCSs.

Clothing choices still remain largely individual and the choices made by BCSs, as for people in general, can be studied following the theories of aesthetics and comfort. Clothing is a silent communicator and an outward symbol that expresses meaning and gives others information about us. The appearance or outer image that develops through this expression of meaning is an interpretation of the psychological components of who we are. Davis (1984) states that clothing serves as a stimulus in social situations, a behavioural response to social and personal variables, and a form of nonverbal communication that stimulates responses in others. It is important to understand the nature of this stimulus for persons undergoing a change in clothing – body relationship (Davis). Bredin (1999) quotes a participant in his study of women's experience with mastectomy as saying, "When you look in the mirror you look grotesque, but when I put my clothes on I don't give it a lot of thought." (p.1116).

Clothing covers the human body presenting a manner of dress which encompasses the outer image as well as any non-apparent intrinsic features of that particular person. Most often, the word clothing is used to define enclosures that cover the body, without including underlying or apparent body modifications. Eicher (1981) defines "dress" as something that includes more than merely covering the body. She includes coiffure, cosmetics, jewelry, and accessories used by the individual. Dress is always with us and is our most intimate environment. It has a significant role to play in the development of self, identify, self-image, and self respect (Eicher).

Clothing also serves an adaptive function when self-esteem is low (Kaiser, 1997). We know that BCSs sometimes have lowered self-esteem after diagnosis and treatment for cancer and that lowered self-esteem is linked to depression and insecurity. If appearance management serves an adaptive function to bolster one's self-esteem, it stands to reason that this strategy will assist in constructing and exerting control over personal social reality (Kaiser). Although most of us make clothing decisions automatically, Kaiser cites studies where women accepted information about clothing from others when clothing was viewed as important, when they were anxious about what to wear, when social context had changed, when they were less confident about dressing well, and when they were more aware of their own and others' clothes. It could be assumed that all of these factors may be present for the BCS.

Clothing selections are based on a number of factors: the physical world that surrounds us, cultural influences, socio-psychological influences, fashion industry influences, and demographic influences (Sontag & Schlater, 1995). They protect modesty, protect us from physical harm, impart status, and provide adornment (Slater, 1986; Kaiser, 1997). Each of these factors holds a varying degree of importance based on who we are at defining stages of our lives. In relation to a BCS, modesty may be important in the early post-treatment and recovery days. Protection from physical harm might be important during this period as healing takes place and sensitive skin surfaces are covered. Protection for parts of the body experiencing edema is also important to prevent abrasion that may lead to infection. Imparting status and providing adornment are factors for a BCS as she assumes a more normal, integrated life-style after treatment and recuperation, such as a return to work, or involvement in a more social environment.

Sontag & Schlater (1995) believe that an interactive process takes place when "change may occur through alteration in states (e.g., physical or psychological) of the human system or the environment, through an alteration of the individual's value system, and in characteristics of the environment (e.g., the worth, quantity, or inherent characteristics of objects)" (p.5). Clothing as object is valued for its attributes and characteristics, which are based on culturally-derived concepts such as aesthetics and functionality. Clothing can also be seen as a human value, where the value interpretation

is centered in the person not the object. The subject (person) is altered by the object (clothing) and the object is altered by the subject.

### *Physical Comfort*

Clothing helps protect the body from pain and discomfort by maintaining a neutral state, a term defined as a pleasant state of physiological, psychological, and physical harmony between a human being and the environment (Slater, 1986; Hatch, 1993). Sontag & Schlater (1995) call the concepts of safety and comfort in clothing “very intangible desirables” and suggest that researchers should focus on these intangible desirables when evaluating indicators of clothing values. It is important to understand if three dimensions of human comfort relating to clothing, defined by Sontag (1985) as physical, psychological and social comfort, are altered by serious illness.

Comfort is often defined as the absence of discomfort or of negative sensations and is seen as one of the most important concepts in understanding clothing (Slater, 1986). There is objectivity in the understanding and relation to discomfort through subjective descriptors that we all use such as tight, itchy, binding, chafing, gaping, and clammy. Garments that feel “invisible” add to a greater feeling of well being by their thermal comfort, sensorial comfort, and body-movement comfort. Alternately, clothing discomfort is one of the most profound stressors affecting optimum human performance and functioning (Li, 2001). As Shivers (1980) comments, “the field of clothing comfort is multi-disciplinary and extremely complex” (p.242). Understanding the theory of physiological clothing comfort is important in determining which garments are appropriate for specific activities and the reasons why discomfort might arise (Shivers).

Li’s (2001) review of the literature and studies on clothing comfort outlines three independent sensory factors in the patterns of relationships in physical clothing comfort: thermal-wet comfort, tactile comfort, and pressure (body-fit) comfort. Her review pointed to the fact that consumer sensory experience varied with physical activity and environmental conditions, such as the seasons of the year. During wear, fabric-skin contact exerts pressure and dynamic mechanical stimulation to the skin. Li shows a map of sensory perceptions of touch and pressure on the female body and found that the stomach, back, and shoulders, along with the upper arms and forearms, were most

sensitive to sensations, after areas of the face. We therefore assume that any trauma to the torso and arms may lead to increased discomfort due to clothing pressure on the body. As consumer trends continue to reinforce comfort as a defining parameter in clothing choice, research on clothing comfort is fundamental to improvement of our quality of life (Li).

Shivers (1980) comments that we make conscious choices about which garments and how many we choose to wear to control the microclimate surrounding our bodies. The natural environmental factors that affect the comfort we feel are air temperature, relative humidity, air movement, and radiant heat from the sun or other sources (Shivers). We know a human body unclothed and at rest is most comfortable in an air temperature range of 28 - 30°C; yet a lower temperature is required for optimal comfort when we are clothed. We also know that the circulatory system controls body heat loss as vasoconstriction and vasodilation control the blood flow to the skin surface. With disruption to the skin surface, these dynamics are changed for a BCS and must affect her comfort level.

Thermal insulation is a critical factor in a cold environment and is another reason why I wish to conduct my research in the fall and winter months in central Alberta. The body has limited thermal insulation based on body mass, and this limitation is increased if the BCS has had insulative layers removed from her chest wall. Layered clothing usually gives us greater insulation value than single layers, yet for a BCS struggling with lymphedema and decreased range of motion in upper extremities, layering may not be an effective means of keeping warm. Stiff fabrics, when used in clothing, generally increase air space around the body when compared with limp, flexible fabrics (Shivers, 1980). Soft, flexible fabrics, however, may be preferred by BCSs because of skin trauma, surgical scars and lymphedema. Shivers noted that spacers in the upper back and shoulder area of garments of firemen's coats helped maintain heat balance by promoting evaporative cooling. She recommends that suitability of clothing for a specific end use is most valid when tested in wearer trials and modifications such as this in garments designed for BCSs may help with heat balance and movement. Sontag (1985) calls for a broader conception of human comfort levels than those found in laboratory settings.

Clothing that fits well is vital to an individual's psychological and social well-being (Goldsberry, Shim & Reich, 1996). They predict that older women's life-style patterns are changing to include more travel, hobbies and recreational activities, sports, physical fitness, and volunteering. These life-style changes contribute to a change in fashionable clothing needs and changed consumption patterns. Goldsberry et al. identified problem fit areas as the shoulders, back, waist, bust, arms, and abdomen. After the review on physiological changes to women's body after treatment for breast cancer, it is apparent that pre-treatment fit problems may become even more pronounced after treatment.

Frequently, studies note that age is the most important variable/factor that affects sizing (Goldsberry et al., 1996). In a study of body measurements of women over the age of 55, it was found that current domestic sizing systems, developed in the early 1940's using younger, unmarried, mostly Caucasian women, do not represent the measurements of older women today (Goldsberry, et al.). Considering that in the United States one in every five people is over the age of 55, this represents approximately 30,000,000 women in that country alone who presently have fitting problems when buying clothing. These are fitting problems experienced before the body is changed by illness. By the year 2030, 101 million people are expected to be over the age of 55 years. It is noted that women's physiological body proportions change with age and it is presently difficult to find stylish and comfortable garments to accommodate these changes.

### ***Psychological and Social Comfort***

Psychological comfort is a mental state of well-being that satisfies affective states such as femininity, sophistication, or having fun (Sontag, 1985). We are considered to be psychologically comfortable when we feel we are dressed in something that agrees with or expresses our self-concept. Sontag indicates that aesthetic characteristics of clothing have a bearing on psychological comfort. Psychological comfort might be defined as choosing what to wear under your own free-will using personal criteria. Social comfort is defined as a mental state of comfort related to social interaction. This state of comfort is attained when we feel we are wearing clothing that is appropriate to the occasion; we are satisfied with the impact we make on others; or we have met some standard of

conformity made in relation to our peers (Sontag; Shivers, 1980; Slater, 1986; Rudd & Lennon, 2001). Sontag states that, although clothing is chosen for one of the three comfort reasons, all three interact in some way.

In her review of studies in the area of clothing and human behaviour, Davis (1984) noted that comfort in dress correlated positively with self-control and extroversion in an individual. Even though individual personality exhibits a set of traits that are enduring, distinctive, and relatively stable across situations, *self-theory* defines the self as merging with the individual's social environment. Positive or negative feelings about clothing arise from an individual's negotiated symbolic image of clothing between the individual and others.

How others see us takes place through perception of the apparel-body construct or the concept of "dress", a four step process consisting of observation, visual analysis, interpretation, and evaluation (Rudd & Lennon, 2001). The perceiver observes the whole form, noting the garment(s) or accessories and how they relate to the body wearing these items. Visual analysis of specific components of the apparel-body construct is then subjectively examined. A socio-cultural context is applied to meaning in the interpretation step. During the evaluation step, the impact of the appearance within the presented context is considered. The idea of self-concept becomes a product of a socio-psychological interaction between the micro environment of self and the macro environment of social and cultural exchange.

### ***Appearance Aesthetics***

Appearance management and appearance perception can be seen as basic social processes bound to our social interactions and our cultures (Kaiser, 1997). Kaiser suggests that to understand social psychology of clothing is to understand the meaning of clothing and how these meanings change within the variable human context. We judge people on physical appearance, a measurable quality that is sometimes culturally and socially prescribed. Research shows that more favorable judgments are made about physically attractive people (Lamb, 2001; Davis, 1984). Davis notes that the first aspects noticed about a person are their sex, age, race, physical appearance, and clothing.

Self-concept and identity are continually assessed through verbal and non-verbal feedback we receive from others (Kaiser, 1997). Identity formation is highly individual and is based on the unique social interaction of individuals within social, physical and biological settings. Roach-Higgins & Eicher (1992) emphasize the importance of the word “social” in connection with dress and its associate meanings, yet caution us to balance the social meanings against the primacy of the biological functions of the human body. Body modification and body supplements contribute to personal appearances. Body modifications have an impact on biological function with both negative and positive aspects (Roach-Higgins & Eicher). Plastic surgery, such as breast augmentation with silicone implants has proven harmful in the past. Yet, breast reconstruction with saline implants or use of the patients own body tissue after mastectomy is seen as positive body modification.

Roach-Higgins and Eicher (1992) define dress as an “assemblage of modifications of the body and/or supplements to the body”. Included in this definition are the concepts of body modification and transformation. Body modification might refer to something such as a tattoo, piercing, or breast implants. Body transformation might be associated with rhinoplasty, a face lift, or mastectomy and/or breast reconstruction (Roach-Higgins & Eicher). Like Eicher (1981), the authors have associated the word “dress” with appearance, clothing, ornament, adornment, and cosmetics. The way clothing works on the body is affected by body structure, proportion, parts, surfaces and movements and becomes part of the information related to others (Rudd & Lennon, 2001). In her review of key developments within body image psychology and cancer-related appearance changes, White (2000) found that the importance of investment in appearance within the breast cancer treatment community has been neglected and when addressed, was guided by clinical interests. Body supplements and body modifications have been excluded from consideration by many scholars when studying dress and identity (Roach-Higgins & Eicher).

Rudd & Lennon (2001) believe that the “model of body aesthetics” motivates behaviours relating to personal appearance by social comparison. Construction and reconstruction of personal appearance are attempts to move away from a group with a devalued appearance, and move one closer to an accepted aesthetic standard. This action

results in a positive self-concept. Roach-Higgins & Eicher (1992) specifically mentioned women with radical mastectomies in relation to this model of behaviour. It could be assumed that a woman predicts others reactions to visible effects of treatment she may exhibit in advance of breast cancer treatment. She undergoes stress in thinking about and dealing with these effects. "Self" has changed outwardly and a redefinition of self-identity is necessary.

Lamb (2001) notes that appearances in the social realities of disabled people are often neglected in disability literature. The tendency is to concentrate on the built environment rather than the near, portable environment of clothing. Lamb suggests that the issue of accessibility is not only related to physical domains but also encompasses the dilemma of finding appropriate clothing for unconventional body shapes. These consumers are restricted by choices of style, color or available materials, and may encounter extra costs in acquiring a suitable garment (Lamb). Fiore, et al., (1996) encourage clothing and textiles researchers to explore the aesthetic experiences of populations that are infrequently studied, such as BCSs.

### *Review of Previous Research Methods*

Women diagnosed with breast cancer and women recovering and rehabilitating after treatment for breast cancer have been involved in many research studies. Most studies are clinically based using a medical model of disease repair. Data sets are based on predetermined criteria that are deemed to be important to breast cancer patients from the perspective of the treatment team (Bredin, 1999; Baron et al., 2000; Smith et al., 1999; Brennan & Miller, 1998; Pozo-Kaderman et al., 1999). Bredin states that there are few studies within the medical and nursing literature that discuss a woman's personal perspective on her experiences with a changed body after the experience of breast cancer.

In a prospective study of life values in breast cancer patients published in 2002 by Lampic, Thurfjell, Bergh, Carlsson & Sjoden, the statement, "I am good looking" was removed from the questionnaire after it was met with "very negative reactions" from some of the women. The authors did not elaborate on why a statement that would elicit such a dramatic response would be excluded from their research study. In studies where



women are encouraged to express their own feelings and experiences, mention is made of outer appearance and of camouflaging body changes (Crooks, 2001; Meric, et al., 2002; Cumming, et al., 2000; Lennon et al., 1999; Bredin, 1999; Brennan & Miller, 1998; Ehmann, 1996).

Morse & Richards (2002) state that qualitative methods are effective if the purpose of the study is (a) to understand an area where little is known, (b) to make sense of complex situations with changing and shifting phenomena, (c) to understand the participants' experiences, the meaning of these experiences, and participants' interpretation of these experiences (d) to construct a theory or theoretical framework reflecting reality, and/or (e) to understand phenomena deeply and in detail. Grounded theory methods allow explanation or theory to be derived from the data itself rather than from a priori knowledge (Morse & Richards). Common data gathering tools in body image studies are interviews and questionnaires. In many cases, research participants are referred by their surgeons or oncologists, giving the studies a very medical perspective (Carver, et al., 1998; Bredin, 1999).

Carpenter, et al. (1999) suggest that grounded theory would help to explicate stages in the process of "positive transformation" for BCSs through the interpretation of their stories. In a review of 115 studies published between 1959 and 1996 of physical and psychosocial research with breast cancer patients, Crooks (2001) found that few projects followed women prospectively. In the studies reviewed by Crooks, researchers took measurements at what medical teams determined were the most stressful points for women with breast cancer. The research instruments used were heavily influenced by psychology and were developed through studies on men. Interviews were not part of the research protocol in these studies, and therefore the opportunity was missed to understand the complex, intertwining processes of illness for these women.

Strauss & Corbin (1990) define the grounded theory approach as "a qualitative research method that uses a systematic set of procedures to develop and inductively derive grounded theory about a phenomenon" (p.24). Sociologists Bernie Glaser and Anselm Strauss, in developing the grounded theory method, believed that (a) researchers needed to get into the field to understand what was going on, (b) theory needed to be grounded in reality in order to develop a discipline, (c) the nature of experience is

continually evolving, (d) people take active roles in shaping the worlds they live in, (e) emphasis should be on change and process and the variability and complexity of life, and (f) conditions, meaning, and action are interrelated and need to be understood in context (Strauss & Corbin).

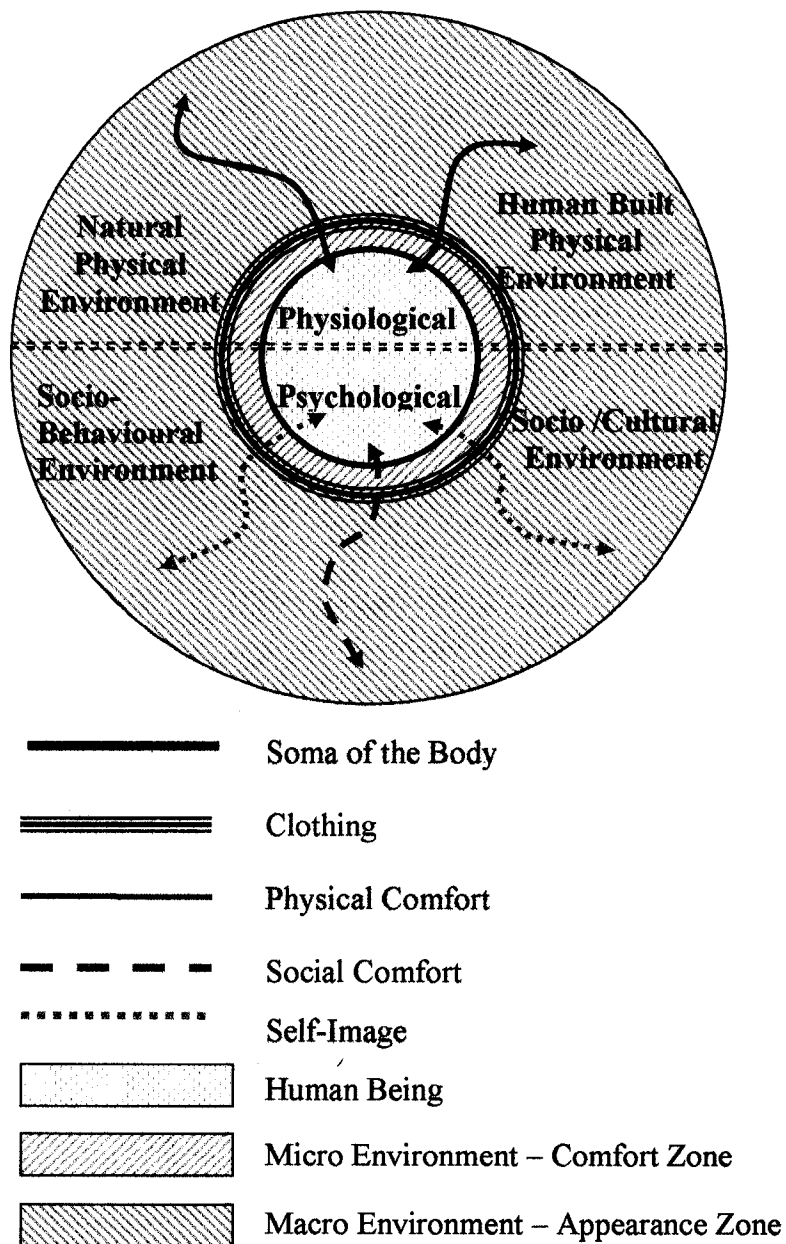
Researchers have found that, through the interview process, participants give a more thorough interpretation of their perception of how others see them as compared to Likert-type questionnaires (Benoliel, 2001; Bredin, 1999; Kieren, Cumming, Walsh, Conners-Spade & Joslin, 2000; Crooks, 2001). Research interviews with patients seem to point to an appreciation of the opportunity to share their experiences (Crooks). Through the research and interview process, empathetic investigators become a quasi support system when they express their concerns for a patient's welfare, genuinely communicate feelings, and listen to the expressions of emotion and feeling (Pozo-Kaderman, et al., 1999).

Based on initial discussions with friends and associates, it was assumed that there would not be a shortage of women who wanted to share their experiences with rehabilitation from breast cancer. Crooks (2001) found that the 20 women in her study were eager to participate in multiple interviews, were keen to talk even as they were being recruited, and wanted to continue with the interviews long after the one hour time limit set for the screening interview had passed. As noted by Carver & Harris (2000), 144 women were willing to participate in no less than six personal interviews. At the end of the 12 month research period, 114 women remained in the study. This suggests that women moving through the experience of rehabilitation from breast cancer are willing to share their information.

### ***Relationship to the Human Ecological Conceptual Model***

Margaret Bubolz (1995) states that the practice of human ecology is grounded in values. Core values involve the survival of humans and the sustainability of the environments that support life, and social and cultural systems. Clothing systems, well-planned covering of the body, are necessary to the survival of human beings and provide an environment that is both macro and micro in relation to the person wearing the clothing (Slater, 1986). The human being is at the centre of the Human Ecological Model

(Figure 1). Clothing provides a barrier between the body and the outside world (macro environment) and in so doing, forms a micro environment apparent only to the central human figure. This micro environment is surrounded by a clothing layer that mediates the effects of the natural world (sun, wind, temperature). This mediation also occurs within the context of the human-built physical world (shelter, temperature control, clothing) and our human-built socio-cultural environment, which modifies behaviour



**Figure 1. Human ecological conceptual model of clothing as near environment**

E. Crown, Adapted with permission.

such as feelings of modesty. Such feelings are based on societal or cultural norms and are influenced by societal institutions. Dressing for socially constructed behaviour is demonstrated in the wearing of uniforms, business dressing, or modes of dress for age-specific groups, such as teenagers or infants. Dress is a societal construct that is dictated by policy, laws, religion, and often, peer review (Kaiser, 1997).

The model demonstrates that there is a constant interchange of information between the individual's unique physiological and psychological zones and the micro and macro environments surrounding that individual. Interpretation of the normal conceptual model of these interactions implies that if the body is changed, change would be expected to take place in interactions on a micro level.

The macro-environmental zone is described as the appearance zone where our outer image is revealed to the external world. This zone is the interactive, or inter-relational zone, between the human being, her personal comfort level based on physical and social criteria, and the outer appearance apparent to others. Clothing is dependent on cultural and social factors and is indicative of symbolic interaction or negotiated meaning and identity. Sontag (1985) found that women in her study were not as concerned about clothing aesthetics when the clothing was not worn outside the home. Yet, when garments would be seen by others, choices were based on a combination of physiological and psychological factors. The Human Ecological Model of "Clothing as near environment" helps identify the elements of this study. My goal was to improve the understanding of the relationships between the BCS and their micro (near) environment and macro (far) environment, buffered by clothing.

### *Summary*

Women who have been treated for breast cancer (the BCS) appear to struggle with fit, comfort, and aesthetic concerns related to clothing. A review of the literature on psychosocial concerns, quality of life issues, body image, and physiological concerns of BCSs, found little reference to clothing and its meaning for these women. The issues of clothing systems and appearance expectations may be trivialized for the recovering BCS.

Early detection procedures for breast cancer imply less damaging surgical procedures exist today, which ultimately lessen the impact of the discomfort and body distortion for the patient (von Smitten, 2000; Ganz, 1999). Muraoka and Gotay (1998) state, however, that more study is needed to provide a comprehensive perspective on the needs of long-term cancer survivors. Sontag & Schlater (1995) encourage researchers to “undertake the study of clothing values by employing values derived specifically from the context under study” (p. 8). The authors encourage the employment of a holistic systems perspective that addresses the interaction of socio-economic, social psychological, socio-cultural and other environmental factors within that context.

A review of the literature revealed several issues key to this study. Women have indicated that they were able to cope if appearances were kept up and differences concealed (Bredin, 1999). Crooks (2001) found that daughters were sometimes the only people available to help mothers purchase bras, provide suggestions to achieve a normal look, and help select prostheses. Baron, et.al (2000) state that factors that aggravate and relieve discomfort for BCSs have not been well studied. Smith et al.(1999) concluded that one of the aggravating factors for the discomfort of PMPS is clothes rubbing.

Even though breast edema is a concern after radiation therapy, O'Rourke and Robinson's (1996) recommendations for the use of cotton sports bras to provide suitable support for the breasts is the only mention made of clothing in their study. One of my clients, who had undergone breast conservation treatment was left with a very large untreated breast and a very small treated breast. The only cotton sports bra she could find to accommodate this drastic difference was made from a very thin cotton jersey. This fabric choice did nothing to support the breast that had not been altered by surgery.

The medical community acknowledges that it is difficult to clothe the swollen arm(s) resulting from arm edema, yet no research studies were found that explored garments and fabrics suitable for BCSs suffering from this condition (Bredin, et al., 1999). Even though lymphedema is treated with the use of compression garments, the most appropriate type of garment and recommended guidelines for their use remain unclear (Brennan & Miller, 1998). The arm can be difficult to clothe and, along with the pain and loss of motion, causes emotional distress and puts in place social barriers (Brennan & Miller; Ganz, 1999).

Recommendations of what to wear during treatment for breast cancer and rehabilitation are scattered and scarce in the various publications reviewed for this study. The clothing recommendations found relate more to medical conditions, do not include comfort concerns, and do not deal with appearance aesthetics in combination with comfort. There is a need for information in this area to aid the BCS in dealing with the healing process, in maintaining her sense of self, and in finding comfortable clothing solutions.

It is important to ascertain the importance of appearance issues for BCSs and to find out if they are receiving the information they need to make complete, informed treatment decisions regarding long term appearance implications. Ehmann's (1996) study is the only one uncovered in the literature review where women, at the time of diagnosis and treatment, explicitly identified appearance and clothing related issues as important. It would be interesting to determine retrospectively if this information was missing and, if given at the time of surgery or treatment, could affect choices made. Women also say that they are bombarded with information early in their diagnosis and they are not ready to think about many of the things that will be important to them later in the recuperation process (Roberts, et al., 2003).

### ***Chapter III Methods***

A grounded theory approach was used for this study. Grounded theory is used when it is implied that a social process has taken place. This approach helps to determine the related stages and phases of the process through analysis of the participant's experiences, with emphasis on the process of meaning-making and change over time. Vital to the understanding of a grounded theory approach is the fact that the direction of inquiry is inductive. Questions are continually asked of the data, resulting in an active form of inquiry of the unique data sets obtained from the participants (Morse & Richards, 2002).

Grounded theory is based on symbolic interaction and produces substantive theory of social phenomena (Schwandt, 1997). Symbolic interaction, a social-psychological and sociological theory, implies that reality is negotiated between people. Consequently, that reality is always changing and constantly evolving through social interaction. Individuals do not just react to set stimuli but take the context they are confronted with and purposely interpret the world through meanings that guide and form their actions (Schwandt).

The literature reviewed informed this study in areas such as appearance aesthetics, clothing comfort, body image, and medical conditions after breast cancer treatment. It did not, however, provide sufficient information into how and why specific clothing choices are made by BCSs. It also did not provide information on products that were needed. A grounded theory was developed in the area of clothing and body image by integrating the experiences of women who have been treated for breast cancer with what was already known about how and why people clothe themselves.

#### ***Summary of the Study***

The research took place in Edmonton, Alberta, a city of approximately 800,000 people in western Canada. Edmonton is located in central Alberta and is surrounded by six satellite communities which lie within five kilometers of its boundaries. Each of

these communities comprises between 20,000 and 100,000 inhabitants. Another 13 communities lie within 20 kilometres of the city limits and represent an additional 40,000 people.

A pilot study was completed two months prior to the main study with a BCS who was known to the primary researcher. The pilot participant took part in a recruitment interview, two personal interviews, and electronic (E) journaling for four weeks. After completion of the pilot project and review of the methods used and data received, another 12 primary participants were recruited by word of mouth and through newspaper articles. Each of the 12 women took part in a recruitment interview, an initial personal interview, a second interview either in person or on-line, and written or E- journaling for a period of six weeks. The interview process and collection of journal entries encompassed a three-month period. Two secondary participants each took part in one personal interview. Secondary participants were classified as support or service providers to BCSs. At the conclusion of the study, and after all data were transcribed and analysed, the researcher met with eight of the primary participants as a group to discuss and confirm findings. Themes and concepts were verified to ensure that areas of concern had been identified and documented accurately.

The study was approved by the Human Research Ethics Board, Faculty of Agriculture, Forestry, and Home Economics, University of Alberta. Confidentiality was ensured through codes developed for each participant. Each tape, transcript, written journal, and E-journal entry was coded individually to identify the participant. Only the researcher had access to the coding schema which was kept separate from the transcribed materials. The researcher worked with Microsoft Office Professional XP<sup>®</sup> on Windows XP<sup>®</sup> from a personal computer in her home, where access to documents was controlled through personal settings and passwords. The researcher set up a special email account with her internet service provider to receive and transmit email submissions only from participants during the project. A private phone line was used specifically for the research project. Participants in the focus group interviews, upon signing the consent form, agreed to comply with confidentiality concerns.



### *Pilot*

A pilot was conducted where one BCS, fitting the sample criteria, participated in two personal interviews and kept a journal for four weeks. The first interview took place at the beginning of the four week period. The participant opted to journal via email, where submissions were forwarded to the researcher's project email address. Entries were received every few days. Her entries related day to day issues and concerns with clothing, along with personal insights on the cancer experience.

After review of the initial interview and the initial journal entries, issues and content were clarified with the participant through a second personal interview. Prior to the second interview, journaling strategies were revised and the participant was asked to continue journaling for an additional two weeks (total six weeks). This period was added to determine if saturation of ideas relayed through the journals would occur earlier or if six weeks would be needed. The pilot participant came down with a debilitating illness four weeks into the pilot, however, and was unable to continue for the six week period. In consultation with her advisors, the primary investigator decided to ask study participants to continue with the initial protocol of journaling for a six week period. After review of the initial interview and journal entries for the pilot participant, probing questions for the main study were revised (Appendix A).

### *Participants*

#### *Recruitment*

For the purpose of this study, the inclusion criteria were:

- *Female breast cancer survivor at least one (1) year post treatment*

This criterion was set to ensure that the effects of treatment were long-term and chronic, and concerns with clothing were not due to the healing process. As stated in the section on physiological concerns, the skin and underlying tissues can be sensitive during treatment, particularly while recovering from surgery. Normal wearing patterns for clothing may not be evident during the period of active treatment.

- *Had undergone treatment with radiotherapy, surgery, reconstructive surgery and/or chemotherapy.*

All these treatments are standard for breast cancer. We know there is trauma to the skin surface after radiotherapy and surgery, and sometimes after chemotherapy, which may affect the way clothing interacts with the body.

- *Between 40 – 60 years of age*

The age criterion includes women who are referred to as "baby boomers". Baby boomers are those persons born between the years 1947 and 1962. It is expected that breast cancer rates will increase dramatically over the next 20 years, due to female baby boomers moving into the "at risk" group to contract breast cancer, which is 50+ years of age (Alberta Cancer Board, 2000).

No one was recruited for this study from an active clinical setting. Participants were chosen through purposive sampling; they were survivors of breast cancer and related treatments.

Primary participants were recruited through word of mouth and through information articles in the Edmonton Journal daily newspaper and the St. Albert Gazette biweekly newspaper. Two participants were recruited through word of mouth. Within a week of both newspaper articles, 11 emails and phone calls were received from prospective participants. In subsequent weeks, three more people contacted the researcher, interested in participating in the study. Snowball sampling was used in one instance when a participant was identified by another woman in the study as someone who fit the criteria and was interested in sharing her experiences. It was expected that data saturation would be reached in this study with approximately 10 – 15 participants. Saturation is achieved when no new ideas or themes emerge through personal interviews or in the journals the participants were asked to keep. Within the context of the clothing experience, in this study saturation was achieved with 13 participants.

### ***Primary Participants.***

From 17 potential participants, one person withdrew from the study prior to the primary interview, one woman had only completed her treatments six months previously and did not meet inclusion criteria, and two women were not interviewed

because saturation was achieved with 13 participants. All women were between the ages of 40 and 60 years and had been out of treatment for at least one year. Five women lived within the City of Edmonton; four participants were residents of satellite communities within a 15 kilometre radius of the City of Edmonton; and three women lived at least two hours from Edmonton. I traveled to interview two of these women in their homes and a third woman agreed to an on-line interview.

All treatments the women had received consisted of some form of surgery, radiation, chemotherapy, and/or hormone treatments such as Tamoxifen<sup>®</sup>. Even though one woman had a second breast removed prophylactically only four months prior to the study, she was included as there was no treatment for cancer involved after this surgery. She felt it was important to tell her story.

Of the 13 participants, five women had double mastectomies; six women had single mastectomies; and two women had lumpectomies. Three of the double mastectomy participants had a single prophylactic removal; one indicated this was for symmetry reasons; and two indicated the removal was to avoid contracting breast cancer in the second breast. The other two women had the second breast removed when cancer developed in that breast.

Of the single mastectomy participants, two women had lumpectomies and then subsequent removal of the breast due to further cancer development. The remaining four women had single mastectomies as their first surgery. One of these women was diagnosed with recurring cancer during the course of the study and is now deceased. The remaining two lumpectomy survivors remained cancer free at the time of the study, one woman for two years and another woman for 17 years.

### ***Secondary Participants.***

Part of the study was to identify sources of information already in place for breast cancer survivors and to see if the participants' perceptions of sources of information matched what was available to them. Initially it was felt that secondary participants could provide valuable information for this study.

Two secondary participants were interviewed: an oncologist, who had worked with breast cancer patients since the 1980's, and a representative of a primary support

group in the Edmonton area. Both women had contacted me personally after reading my article in the Edmonton Journal. The oncologist was included because this was an opportunity for me to understand the relationship between the professional and the patient. The oncologist was also able to clarify information relayed by participants regarding medical situations.

The representative of the primary support group was interviewed because most of the participants indicated they had contact with this group at an early stage of their cancer experience, and the representative had indicated in our initial conversation that there were no clothing problems for BCSs that she was aware of. After primary participant interviews were completed, I wanted to come to a better understanding of why she felt clothing was not an issue for BCSs within the context of a primary support group's extensive contact with these women.

### *Data Gathering and Coding*

Data gathering from primary participants consisted of:

- A recruitment interview
- A face-to-face personal interview(s)
- Journaling for a six week period
- A second interview; personal if journals were handwritten; women who were emailing journal entries were given the option of a personal interview or answering additional questions on-line
- Participation in a debriefing session after data had been compiled and theoretical statements were formed

### *Interviews*

Participants in the study were given the option of being interviewed either in their homes or in the social science research facility, Department of Human Ecology, University of Alberta. The specific location was decided during the recruitment interview and was noted on the Informed Consent form (Appendix B). The interview

was held in the participant's home only if she guaranteed that there would be no disruption for a two hour period. Twelve of the 13 participants were interviewed in their homes. One woman was interviewed on-line. The interview was held at a time mutually agreed upon by the participant and interviewer. Most women were able to provide a quiet, uninterrupted environment for our interview. Phones, pets, older children, and spouses sometimes intruded, but for the most part were not a problem.

After settling into a quiet, relaxing environment, the participant completed a simple demographic form (Appendix C) and the consent form (Appendix B) after reading the information letter (Appendix D). I then moved into the discussion with the leading question, "Could you relate your post-treatment experience with rehabilitation and recuperation from breast cancer." Because this question was unstructured, participants were free to set their own pace and to include what they felt was important. For the on-line interview, the participant was emailed the opening question after receipt of the signed informed consent and completed demographic form.

A set of probing questions (semi-structured and open-ended) were developed (Appendix A). They were used when it was felt the participant had exhausted her response yet had not brought up issues relating to clothing and body image that were of interest to the researcher. As interviews progressed and journals were reviewed, subsequent themes arose which required clarification by the participant and necessitated that some guiding questions be reframed, removed, or added. After reading the monologue forwarded by the on-line participant, I prepared a set of open ended questions based on the prepared list of guiding questions. Questions of clarification specific to her story were also included.

Only two women in the main study opted to be interviewed in person for the second interview. The seven others, who I had originally interviewed in person, chose to have the questions forwarded to them by email. Four women were not interviewed a second time. One woman could not be contacted by phone, and the other three were not given a second interview because I had no clarifying questions to ask them. Their journaling did not raise any additional questions within the context of their experiences.

## *Journaling*

During the recruitment interview, all participants agreed to keep a journal. This was confirmed at the primary interview. Participants were asked to keep a journal over a six week period following the primary interview. The task of the participant over the six week period was explained as follows: “I ask that you keep a daily journal over the next six week period to record your feelings and experiences with post-treatment experiences of breast cancer, especially those related to dress and clothing. You are encouraged to write as often and as much as you like.” Three journals were handwritten and the other ten were submitted as E-journals. Handwritten journals were picked up two weeks into the schedule, photocopied, and returned to the participant. The photocopies were then transcribed as Word<sup>®</sup> documents. E-journal entries submitted to the researcher were easily formatted into Word<sup>®</sup> documents, an expedient way to review the notes and develop themes from the data sets.

Of the three handwritten journals, one woman did a substantial amount of journaling; one did no journaling; and another did only minimal superficial journaling which indicated to me that she had nothing to add from the initial interview. This latter woman had a double mastectomy three years earlier and as she indicated in the interview, her problems were more pronounced with a single mastectomy than with a double mastectomy. She had resolved a lot of her clothing and comfort issues, as she was tiny and chose to not wear the prosthesis. Comments made during the interview regarding clothing and comfort were validated by her lack of journaling.

Originally, I had assumed that more meaningful email journal entries would be achieved if there was no contact with the participants. This strategy was employed during the pilot. Yet during the course of the larger study, as E-journal entries were received, the women sometimes appeared to be continuing our interview dialogue and asked questions that did not seem rhetorical. Further along in the journaling process, I responded to their journals and questions and delved deeper into their experiences by asking more questions based on their responses.

### *Debriefing*

The debriefing session took place in the Department of Human Ecology social science research facility, University of Alberta campus, three and a half months after the interviews and two months after journaling were completed. Twelve of the surviving participants were invited to participate and eight attended. The session was audio tape recorded.

In a round table discussion, the theoretical framework of the self-preservation process, which supported the importance of clothing, was presented to the group. They were asked to agree or disagree with the model and were invited to comment. Twelve statements formulated from the participants interview data were then presented to the group. These statements represented key concepts which arose from the data and which were used to develop the theoretical framework. The women in attendance were invited to comment on whether they agreed or disagreed with the statements and to offer clarification if necessary. Discussion of the key concepts provided further insight into the intended meaning of comments made during the interviews and clarification of those points was incorporated into the Findings and Discussion. At the end of the discussion of the 12 statements, I presented a list of eight primary concerns which had been stated by participants in the interviews. Although the question was originally asked within the context of primary concerns relating to clothing, participants in this study sometimes indicated that other areas concerned them and these areas related back to clothing in some way. Each participant in attendance was invited to rank the statements in order of personal relevance, with 1 being the most relevant and 8 being the least relevant. They were then invited to list resources they had used at any time before, during, or after their breast cancer experience, and to rank them in helpfulness from 1 to 5, 1 being the least helpful and 5 being very helpful.

All personal interviews were audio-recorded and transcribed verbatim. Transcription took place as soon after the interview as possible and was completed prior to interviewing a subsequent participant. After initial interviews were transcribed into Word<sup>®</sup> documents, they were numbered by paragraph, printed, and analysed by the researcher to identify early themes and categories. Documents were then entered into the NVivo<sup>®</sup> qualitative software program and, because the analysis was not linguistic in

nature, transcripts were edited for analytical purposes to remove intrusions and extraneous dialogue. Full transcripts were kept on file. NVivo<sup>®</sup> was used to code the data records in-depth so that the categories and concepts could be retrieved through node searches.

The NVivo<sup>®</sup> program is designed to handle rich text records. Links to external data sources, such as web sites, and internal documents were embedded into each woman's story at that point. For instance, when participants referred to treatments I was unfamiliar with, such as Taxotere<sup>®</sup>, I was able to pull up information on the web and link it to that specific place in the document. Every time that document was opened and I needed to refresh myself on the information or look for additional information, I could easily visit the website. With the assistance of this software program, information on participants was stored through the use of attributes embedded within documents and nodes. For instance, the demographic information on each participant was linked to each participant's document so that at any point in the analysis, it could be retrieved. This was helpful while I was becoming familiar with the participants and their stories.

As journal entries were received via email, all identifying information was removed, each was coded by participant, and the entry was formatted into a Word Document. If a response was warranted and further clarification was necessary, the message was sent off as soon as possible. Although some entries were longer than others, the average length of a journal entry was a single spaced 1/2 page of text.

As the interviews progressed and the journals and E-journals were reviewed, common themes or nodes relating to post-treatment breast cancer rehabilitation emerged from the data. Emerging categories reflected concepts borrowed from the participant's vocabulary. As stories were told and concepts formed, unique data sets created a picture of common story lines across experiences. Some themes and concepts from the interviews were enriched by journal entries. Continual comparison was used to link the views and experiences of the participants. This analytical strategy is referred to in the literature as the "constant comparison" method and is an ideal way to identify subtle but possibly important differences and similarities in the women's stories (Morse & Richards, 2002). As I compared similarities and differences, the coded category or



concept allowed identification of underlying uniformities. Data collected from participants continued to provide information to support and sharpen definitions of concepts throughout the gathering process.

Interview transcripts and journal entries were reviewed only by the primary investigator so there was no need to develop coding strategies between researchers. As documents were reviewed, a preliminary system of coding was developed which identified obvious themes. A number of concepts introduced by the participants fell outside of the scope of this study. Within the context of the breast cancer experience, the primary investigator was able to formulate a basic process which incorporated divergent yet related themes. This process forms the framework for analyzing the results in Chapter IV.

## *Chapter IV Findings & Discussion*

When asking the question, “Could you describe your experience with rehabilitation and recuperation from breast cancer?”, I assumed responses would describe the period after treatments when women were returning to normal routines. I was always surprised when the participant came back to the period of diagnosis. It became clear after reading and rereading the interviews that the process of recovery and recuperation was one of change and adaptation, and the diagnosis was the beginning of reimagining, redefining, and renewal within the context of serious illness. Reimagining is a term used by Norris, Kunes-Connell, & Stockard Spelic (1998) and is described as a process of moving forward in response to significant alterations in the physical appearance or functioning of the body. The notion that perception of “self” is more a process than a state (Kaiser, 1997) is evident in the stories of the participants.

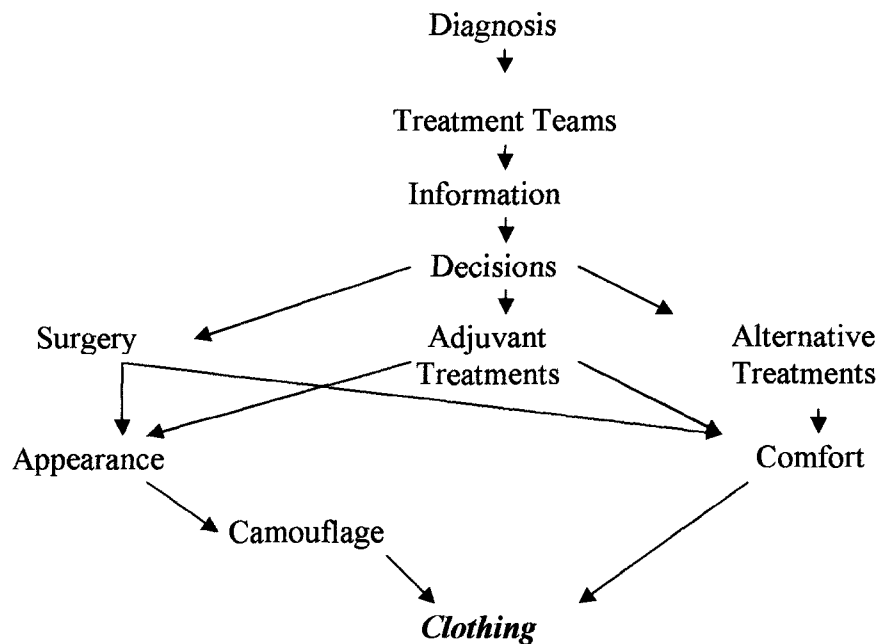
A diagnosis of breast cancer precipitated a flurry of activity for the woman with various treatment teams, who provided her with information regarding decisions she would have to make. In spite of the terror she was feeling at the diagnosis, she also attempted to find information on her own. Treatment options were usually surgery, chemotherapy, radiation, and possibly hormone treatments, which are covered by health care. Alternative treatments such as acupuncture, physiotherapy, and massage therapy, which were very beneficial to healing, pain, and discomfort management, were usually not covered by medical coverage. Unless the woman had a good private health care plan, she was responsible for paying for those extra services herself.

And I go for massages and now I’ll be going for acupuncture every two weeks and massage every week in my home. (D-21)

Physiotherapy, you get five visits or something. But all physiotherapists charge a fee so I couldn’t afford that. I did try the chiropractor. I met a wonderful acupuncture student, who is now sort of my acupuncturist at Grant MacEwan. So she gives me free acupuncture. I found that massage was really beneficial. But at \$75 a crack. That’s not covered anywhere. (A-21)

After-effects of treatments contributed to appearance management problems which required women to think about strategies that would camouflage body changes.

Comfort issues also became a problem fairly quickly as BCSs altered wardrobes and dressing patterns to accommodate healing and a changed body. Clothing, which included over and undergarments, became a tool for women recuperating and recovering from breast cancer treatments to assist them in addressing comfort and appearance issues. A matrix of themes arising from participant stories shows the complexity of the process (Figure 2).



**Figure 2. Important themes reported by BCSs in the recuperation and rehabilitation process**

Excerpts from the interviews and journals are found throughout the Findings and Discussion. The following convention has been used to identify all quotes and to ensure that they are easily traceable to the originating document:

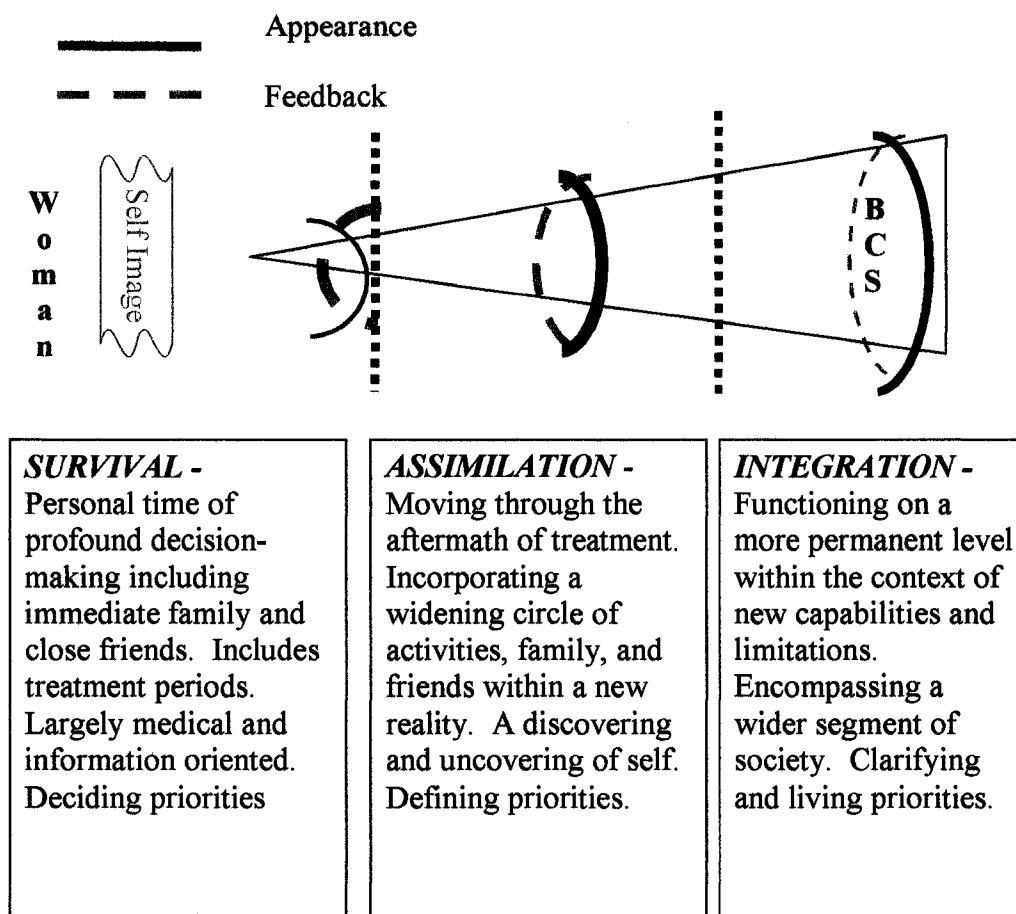
- Quotes from the primary interview are noted by the use of the first coded initial of that participant and paragraph number i.e. A-21

- Quotes from journals are noted by the use of the first coded initial of that participant, the initial “J”, and the journal number i.e. A-J4
- Quotes from second interviews are noted by the use of the first coded initial of that participant, the initials “SI”, and the paragraph number i.e. A-SI3
- Quotes from secondary participants are noted by the use of the initials “SP”, the initial of the participant, and the paragraph number i.e. SP-S-18
- Quotes from the debriefing session are noted by the use of the first coded initial of that participant(s), the initials “DB”, and the paragraph number i.e. D, E, G-DB18

### *Core Concept of Self Preservation*

A framework that I describe as the process of self-preservation (Figure 3) was developed from the emerging themes (Figure 2). Self-preservation is defined as an instinct to preserve oneself from harm or destruction (Steinmetz et al., 1984). The stories began with a description of *preservation of the body* regardless of the repercussions and ended with *preservation of the self* where personal growth and awareness initiated by the cancer experience were incorporated into a new understanding of “self”. There was an increased awareness of the role each woman played in relation to those around her and the process helped her define and clarify her priorities as she moved through illness to wellness. The journey of adaptation to a changed body and self-image after breast cancer identified the framework around which clothing took on new meaning and relevance.

*Survival* means to immediately accept the situation as is and consciously decide to use all resources available to make it through (Jenkins, 2003). An important component of survival is seeking a diagnosis when you realize that something is wrong and that it may be a threat to your wellbeing. Even when medical teams told the participants that there was nothing to worry about or nothing was wrong, almost all of



**Figure 3. Model of the three stages of the process of Self-Preservation**

the women spoke of “gut instincts” or a 6<sup>th</sup> sense in knowing something was wrong with their bodies, “I just knew, I knew inside my heart”. (F-10) Important to this study is the implication that, as suggested by other studies, some women are conditioned very early in the breast cancer process to have their needs and concerns disregarded or trivialized (Bredin, 1999; Crooks, 2001).

We’ll start by saying that it was a shock to me to find out that it was breast cancer because I had been going to a doctor for four years with a lump in my breast. He always said its just a water filled cyst. Don’t worry about it. On holidays, my breast started to hurt and I went immediately to the doctor for another mammogram. The radiologist hit the roof. “Didn’t he do anything about this 2 years ago when I told him to?” I saw my surgeon on Friday and on Tuesday morning I was in surgery. (K-2)

Diagnosis of cancer became the impetus for self-preservation. The diagnosis affected each woman physically and philosophically. Many expressed a desire to return to their former lifestyles as quickly as they could after surgery. Where possible, they began to take up activities enjoyed prior to diagnosis and they began to take an active part in their communities. Although comfort was a priority, appearance aesthetics was also important as women tried to hide the effects of treatment and to camouflage their disfigurement.

*Assimilation* means to take in an experience and make it a part of one's self (Steinmetz et al., 1984). Once the goal of preserving "life" was secured, the new goal became to preserve themselves as women and individuals, and through assimilation and integration, came a greater understanding of "self". Although comfort was a priority during the survival phase, the assimilation phase was characterized by women returning to more normal routines after the hectic schedule of treatments. In spite of continuing physical problems relating to after-effects of treatment, many women believed that they would return to a pre-treatment physical condition. They were more prepared to tolerate discomfort during the assimilation phase, thinking this would be something that would "go away" with time. Positive or negative feelings about self-image took on more meaning based on feedback from others. Sometimes the harshest critic of her appearance was the BCS herself.

BCSs continued to be fearful of recurrence and subconsciously prepared for their death. Although some women returned to paid jobs during this phase, some did not, and early retirement was common in this group of 40 – 60 year olds. The decision to retire had a significant impact on lifestyle and provided enhanced opportunity for self-fulfillment and growth.

*Integration* means to make into a whole or to complete (Steinmetz et al., 1984). The integration phase began when BCSs had been out of active treatment for some time and had gained perspective on their experiences. This phase was indicative of a period when they began to realize that limitations were permanent and would require continual remedial work. Women began to anticipate a longer life than first envisioned. If this was their first cancer experience, they began to incorporate lessons learned about themselves and their families and friends into a more realistic representation. If this

was a second cancer experience, as was the case for five of the participants, integration began within a much shorter time frame.

Understandably, phasing for each individual was different. The importance placed on comfort, camouflage, and appearance aesthetics was varied with the psychological and physical state of the participant. During integration, women often had to choose between being comfortable or camouflaging their treatment effects. Few women found that both qualities could be embraced completely. Each woman also placed different importance on appearance aesthetics and comfort. Findings from this study indicate that women may become “stuck” in assimilation and, as suggested by other studies, find it difficult to integrate the changes brought on by breast cancer in a meaningful and positive way.

As the model of self-preservation emerged (Figure 3), I was reminded of the ripples in a pond when a stone is dropped. Like ripples, effects of the disease and treatments worked their way through the woman’s reality and all aspects of her life. BCSs were very sensitive to feedback from others and many times indicated that how others saw them, or how they felt others saw them, was an important internalizing mechanism for them. Sometimes just the premonition of rejection was enough to hold a woman back from doing something that was important to her recovery.

I don’t mind speaking up but I do have a wee bit of a problem with [City X], because this business I ran was very high profile and I’ve been humbled greatly. I’m not a babe anymore. I know they wouldn’t care. My ego would have a hard time with it because I’ve changed. My body is not... I’m not a babe anymore. (B-252)

For another woman whose mother was experiencing ill health and other stressors, she chose not to see her mother or seek emotional support from her during diagnosis, surgery, and early chemotherapy treatments even though they were very close.

I was wearing my wig and she [her mother] thought it was actually my hair. And she goes, “Oh you look good.” Because it was at a point where they [her sisters] brought her and I wasn’t down. I put on some makeup and I looked pretty good. And that was the first time she saw me in a long time, so it was good. (C-174)

### *Survival*

The survival phase of self-preservation took the woman through the stages where she realized something was wrong with her body, on to a diagnosis of breast cancer, and through the appropriate treatments.

Well I think my story starts at the day of diagnosis and the overwhelming emotion you feel (begins to cry) when you're diagnosed with breast cancer. You can't breathe; it just sucks your life away for about 24 hours, that's how I felt it. (F-P4)

Women who have been diagnosed with breast cancer are always given the option of which treatments they will choose. For some forms of cancer, surgery may be the only recommended treatment. The treatment period can be anywhere from two weeks, if there is no adjuvant therapy, to up to a year with chemotherapy and radiation treatments. Although the women related that they were encouraged to find out information about each of their treatment options and outcomes, they admitted that they were in shock and were not receptive to information. They related how they could not clearly understand specifics or even comprehend outcomes.

I think some of the difficulty came in at the very beginning around the recuperation because I didn't totally understand it, and even though the doctor was a wonderful doctor and explained everything to me, I was in shock about hearing I had cancer and had to go into the hospital so quickly for a mastectomy that I couldn't absorb everything quickly. (D-2)

I would say in afterthought I probably didn't feel well informed but there wasn't time to explore other areas. You just wanted to get everything done so you could get back home and get to work. (H-131)

From that point on then the ball starts rolling and you're going to see a surgeon and he's telling you that you're going to probably have your breast removed and they do the biopsies and things like that and you just go from appointment to appointment and get through it. It's a little easier than the first 24 hours. I think the first 24 hours are the worst because when you think of cancer you always think of a death sentence. (F-12)

They called me earlier than they should of because they had an opening. So that was good. I went in at the spur of the moment, which didn't give



me time to think. And they did the operation, which was extremely scary. I remember being very frightened. (C-7)

However, even decisions made by the women were not always taken into account by the treatment teams. Participants sometimes felt that their wishes had not been carried through and they were left to deal with the repercussions.

I begged for a mastectomy 18 years before and was told I was too young and really it was the shock of the thing that I would think clearer afterwards. Which was garbage. My initial choice when I was 37 years old was to have a mastectomy. I had no idea why, I just thought, "Let's get rid of this". (P-24)

The surgeon talked to my husband and myself and stated that he felt that the cancer would go to another part of your body and he was not willing to take off the left [breast]. After, when we went back with the second operation, he still maintained that this was the best way to go. But I maintained that it probably wouldn't have gone into my lymph nodes if they would have done it sooner so that's why I feel the second one [mastectomy] was worse than the first one. (G-10)

In some of the first visits to the surgeon, the possibility of reconstruction was broached so that the surgeon could plan for and accommodate the needs and desires of the woman. Even when women expressed a desire not to have reconstruction, in some cases the surgeon still left excess skin to facilitate the procedure "just in case the patient changed her mind". Understandably, when a woman is diagnosed, all she is thinking about is surviving. Surgeons may have experience with women who, further down the recovery and recuperation road, have indicated they wished they had more options available to them regarding reconstruction. Even so, decisions made by women, after careful consideration, were sometimes ignored by treatment teams.

I have lumps that are hard [folds of scar tissue on her chest] all of this stuff, is painful and fills up with water. I was very clear. No, I did not want reconstruction. So now I'm seeing a plastic surgeon about taking them off. I've seen some women with the post op and I haven't seen anybody that's as ugly as me, but I feel butchered." (B-59, 69, 341)

Initially in the survival stage, the core goal of the women was to preserve life, regardless of the physical cost. Many women went into their surgeries and treatments just wanting the disease to be gone, and did not give a lot of consideration to the aftermath. Participants in this study indicated that they were not told what the

aftermath would be. Decisions were based on chances of survival and seldom on how treatments would change the body.

Okay, this is the deal, this is the problem and how do you solve it? There is only one way to solve it. At that time then I just decided, while I'm down here they might as well do both of them because I don't want to come back here. (A-42)

I'd love to negotiate this but I had cancer five months ago. I am not taking any chances. Take them off. I will deal with the aftermath of having no breasts. My children needed me. If they said it's in your arm I'd say chop the arm off. (B-69)

And I said to him [the surgeon, after her second lumpectomy], "If they prove to be breast cancer can you please take them off because they're too little to be such a big problem and I don't want them anymore." (E-18)

I try to look as normal as I can but maybe it's because of other people's comfort. But my doctor had mentioned that I could go for reconstructive surgery and I did find out early on that it is covered through Alberta Health Care, but my reason to my doctor was, "I'd be ready to go to the hospital in five minutes to have my other breast removed if I knew it would keep me from having to go through cancer treatment again." And I think I probably would have felt better if they had just removed both breasts, know what I mean. (K-181)

After surgery, women recognized that they had some control over finding solutions to their problems. They were actively involved with treatment teams and were usually only a phone call away from help for any problem that arose in the course of healing from the surgery and during adjuvant treatments. Women related that the whirlwind of chemotherapy and radiation treatments provided a hectic period in which they did not have time to think about the future. Many of the participants described rehabilitation and recuperation as a straight forward process.

So with the recuperative part, I recuperated very quickly. I bounced back very fast, except I caught a staf infection in the hospital, not in my breast but in my lung. (D-2)

Anyway, back to the recuperation. The worst part was getting the drains out, that really hurt. And then I just faithfully did the exercises because they teach you the exercises in the hospital. (F-24)

During the survival phase, when faced with a life-threatening situation, women became more aware of their own personalities. Self-awareness was a fitting word to describe the emergence of these positive qualities.

And the one thing I've learned from that is cancer isn't a death sentence and it's the biggest lesson I've learned from my experiences. I mean it's scary but it's something you can deal with and I've learned a lot from it. Not that I wanted it, but I'm thankful I had it because I saw things in me, in my family and friends that I never expected I would ever see. (F-12)

God never gave me a fatal illness; he gave me something to shake me up. And it did. And I've taken control of my life, quite frankly. (B-77)

It [cancer] told me who I was. I was the same person before but I don't think I fully knew it. But the day I think I was diagnosed I had to look at myself and say "What makes up you as a person because you're going to need it now." And I did find me. And it was the same me that had been there with fewer compromises. (P-177)

In a strange way having cancer has been a blessing in that it has taught me so much about myself and brought me into contact with so many people I would not have otherwise known. I hope that every day I strive to live life well and to make the best of the precious gift of my life. (I-89)

These comments demonstrate that the women had experienced a growth process.

During the survival phase of the process, comfort and appearance issues were important. Some women wanted to camouflage treatment effects by covering a hairless head. Comfort issues related more to finding clothing that would accommodate healing from surgery, radiation burns, and sensitive skin from chemotherapy. Although participants were concerned about appearance and comfort, they were also looking forward to a time when things would be back to "normal."

### *Assimilation*

The next phase in the process of adaptation to breast cancer was assimilation of physical changes with personal lifestyle. There was also a growing awareness of the effects of treatment on the BCS. Up to this point, the participants had been dealing with clothing and comfort issues, along with the resulting change in body shape, as

though these concerns were temporary. There had been an assumption that struggles with comfort and symmetry would become easier after treatments and healing were completed. The lingering after-effects were unexpected. Women did not have a good understanding of the long-term implications. During the assimilation phase, fear and confusion also consumed participants after leaving the comfort of daily or weekly support systems within the medical community. After treatment regimens were over, BCSs finally had an opportunity to sit down and consider the consequences of what had happened to them.

So I thought okay, this is really eating at me for some reason. I need some answers. I can hear now better because there's a space of time and so what I need to know is how does this cancer progress. (D-35)

And then you had some time to think. I called it the aftershock. My mom was ill by then and it was, "Oh my god." I was having a hard time every day without crying. So I was quite low. (C-237)

My newest doctor at the Cross assured me that the tenderness in the radiating area is very normal to experience for quite some time after treatments have stopped. (I-J14)

The doctor I saw about reconstruction said that he knows no one who has had lymph nodes removed who is not affected in some way on the surgical side. (I-J9)

But more stressful than losing the breast was the back pain that followed, the shoulder pain that followed. That was not addressed by the medical community. They just did not know what to do about it. (K-48)

I don't realize how "not great" I feel until I have some relatively pain free days. (P-J8)

You get an ache or tiredness in that side [the surgery]. Sometimes you just have to take your clothes off and rub it down with some salve and go to bed. (H-119)

Recuperation, it's a long road. Rehabilitation has been frustrating. I don't think I fully feel recuperated. I asked my oncologist the other day if I actually would be fully recuperated and she didn't think so. (A-2)

We were told that things would return to normal once we got over our initial healing. (G, P, K, F – DB 112)

But there's a new problem that's crept in and that you've mentioned Taxotere<sup>®</sup>. Taxotere<sup>®</sup> is a drug like erythromycin and will cause hair loss, but I have seen patients not recover their hair after Taxotere<sup>®</sup> and they're left with thinning on top and some have been quite philosophical about it and said, "Well you don't have problems if you're not alive." I haven't had anybody be really bitter about it but I felt very badly for them. (SP-S-344)

During the interviews, and corroborating my feelings that clothing should be an issue for BCSs, women related the following general physical problems directly related to treatment of the breast cancer:

- skin tenderness
- residual pain in the chest area
- poor posture
- numbness in affected arm and chest area
- some limited range of motion on affected side
- fatigue and low energy levels

Those directly related to surgery were:

- scarring
- tenderness in drain site scars
- excess skin on the chest and under the arms
- asymmetry due to the loss of a breast
- lymphedema due to lymph node removal
- pain in chest wall (post mastectomy pain syndrome)
- fibrosis

Those directly related to radiation were:

- discoloration
- spider veins
- tattoos
- scars from burning
- dermatitis
- lymphedema from radiation damage to remaining lymph nodes
- sensitivity of radiated skin to sun (UV rays)
- fibrosis

Those directly related to chemotherapy were:

- weight gain
- tender feet due to loss of toe nails
- sensitive skin
- heartburn
- nausea

- loss of taste
- metal mouth
- mouth sores
- menopause
- temporary hair loss over entire body

Those directly related to hormone treatments (Tamoxifen) were:

- swelling of extremities, particularly hands
- weight gain
- hot flashes

Through the stage of assimilation, participants began to branch out into the community again once surgery, chemotherapy, and/or radiation treatments were completed. In spite of significant physical problems, the women were getting on with things as expected. Participants indicated that many times during this phase they were discouraged from discussing their problems and fears, and that friends and family wanted to put the experience behind them. Sometimes they were the ones who did not want to talk about their situation. Women, however, missed having the opportunity to discuss ongoing problems or concerns impacting quality of life.

I had to talk about dying. If I was going to die I wanted to talk about it. I had a very dear friend who'd say, "Here we go again, the death thing." I stopped talking to her about it. One day I just said to her, "Yes, some days I just have to talk about death." But I realized not with her. (D-137)

Well, we all go through this crisis afterwards. "Whoa, what the hell happened?" ... and I know it's an issue and also you tend to isolate yourself because you don't want to talk about it anymore and then there is absolutely a need for someone or something to happen that women can adjust to the changes more gently. Because, for the most part you're on your own. I mean, there are resources to find. (B-311)

I am still a cancer patient [after 17 years] but I'm still cancer free. And you can't talk to the ordinary people about that because they think if they remove the cancer it's gone. (H-57)

Breast cancer is not a disease that is eradicated by treatment, and coupled with the after-effects of treatment, many of the participants related the fear that it might still lurk in their bodies. The women also related that their changed body was a reminder everyday of what they carried with them: fear of recurrence, fear for their female

children, fear for the partners that would be left alone, and fear that further treatment would cause more distortion and damage.

I'm not sure how other cancer survivors feel. I wonder if they are able to forget completely about having had cancer and just move on with their lives. I find that it is impossible to pretend it never happened when every time you undress you are faced with the reality that "Yes, I had cancer." (I-74)

Maybe because when I see myself in the mirror without it [prosthesis] in those clothes [ones that are too form fitting] I am reminded of the cancer. (J-J8)

But the other thing for me was the fear. I had finally to come to grips with what was my real fear around this and it wasn't the dying. It was waking up one day and being full of cancer and having three weeks to live or six weeks to live. And I thought I can't handle that. I need some space of time to die. And so I talked to my family doctor because the oncologist at the Cross wouldn't see me. (D-32)

So I would go and I would stay with them in the hospital or overnight if they didn't want to be alone. And I didn't see too many of them frightened at the very end. They were glad to go. Now somewhere in there I think that was self-preservation on my part. I wanted to see what the road ahead was and the only way you can do it is to face it. Obviously it wasn't happening to me right then. So whether it was terribly dysfunctional or very healthy I don't know but I came out with lots of survival skills because of it. (P-64)

### *Integration*

During the integration phase, the women were seen as long-term survivors. It seems there is a turning point at approximately the two – three year mark where they come to terms with the fact they may not die prematurely. This period is marked by a noticeable effort to make the most of life. Awareness of self gave the women in this study renewed strength and initiative to move forward. They valued meaningful relationships with family and friends, had learned valuable lessons from relationships that had fallen along the way, and had a better understanding of their priorities.

And then there was an actual transition point, it was a week ago, something shifted in my being. And I went in to see my therapist and

what he said that was invaluable, “You know you’ve turned the corner and you’ve made the decision to live. Up ‘til now you’ve been worried about dying and so you’ve been preparing for your death. So whatever hit you yesterday, you made a decision to live and it changed everything.” So I’m not into preparing to die anymore, I’m more moving into being more creative, doing more things I want to do. Well, I said that before but it wasn’t in my being yet. (D-198)

The “todays” rather than the long term future became my goal. (P-J4)

A successful transition from assimilation into integration meant that the fear of premature death was no longer an overwhelming issue for the BCS. She now understood that lingering physical problems would be chronic. At this point she was able to decide what her priorities were and how she could accommodate comfort with appearance considerations. Sometimes this meant she chose discomfort to meet an appearance standard. She realized her value lay more in living meaningfully and productively, and it was best done on her own terms.

Deep down I think to myself, “I’m damn glad to be alive, I don’t care what weight I am”, and I will go to whatever weight I feel good at. The moment I don’t feel good I will do something about it. (P-151)

### *Creativity*

Creativity is a vital characteristic of a successful survivor (Siebert, 1996). Creative approaches to extricating oneself from perilous situations also indicate a tendency for applying creativity to other areas of life. Participants were asked to describe what part creativity played in their recuperation and recovery process. Within the context of this study, participants indicated that creativity was demonstrated in their vocations, and in artistic endeavors of performing arts and visual arts. They had difficulty describing how and why they were creative very early in the process of self-preservation. Further along in the journey, creativity became more of a guiding force and a way to channel energy into something productive and meaningful. Some women used creativity to take their minds off their troubles. Others used hand work to keep arms flexible and supple.

I’ve just bought an easel. I’m drawing. Being creative helped me to overcome just looking at myself this way and I guess having a creative



spirit, I was able to look at, okay, I'll do this with my clothes. See I can change this. (K-162)

Women considered their abilities to decorate and maintain an attractive home a creative outlet. They talked about gardening and expressing their creativity through physical exercise and movement. They talked about raising children and helping with grandchildren. They talked about baking and culinary skills in a creative light. They described creative items and processes they developed as ways of getting through the cancer treatments.

Actually one of my coping mechanisms was my "Reason Book". It was pictures of all the things I loved. It was the reason I was going through all this crap. Family, friends. This was my son in Japan; this is what I looked like without hair, pictures of when our kids were little, these are my sister's kids. (J-49)

And recently I've taken up art. I found doing something creative was very important following each treatment. Following the cancer and during the radiation I was told to keep that arm moving. I had a quilt top made and I quilted it during that period. I quilted it from the centre out by hand because this motion, pulling the thread up was exercise every day. It was spiritually nice to see this quilt come together also it takes your mind off it. (K-152)

I have been singing with a group for the past 12 years. We meet on a once a week basis. It was one of the things I missed the most when I was away from home for 6 weeks having radiation treatment. It was so good to get back home and start singing again – another kind of therapy. The other thing that I do for myself creatively is sew. Two weeks before my diagnosis I had started on my very first quilt. I quilted like crazy through the mammograms and ultrasounds and as I waited for biopsy reports. It was a victory of sorts when I finally regained enough arm strength post treatment to be able to handle the quilting of the queen size quilt. (I-SI-139)

One participant, who did not participate in adjuvant treatments, used creativity as a support system.

The Arts in Medicine program was different. We all got together to do something, to create something. And sometimes we talk about cancer just out of the blue, sometimes we wouldn't. We'd talk about normal everyday things, but it was all uplifting, positive, and when we walked out of the room we all felt better. I can't say that for everybody. I felt enriched and enlivened. I felt listened to so if I had something specific to say there was always somebody to talk to. (D-137)

Although participants early in the self-preservation process could not articulate their creative abilities, it was demonstrated in the descriptions of how they lived their lives or how they approached challenging situations. They were not yet in tune with how they were channeling their creative forces.

Rehabilitation to me means that you are actually being proactive to do something to make yourself feel better like in the physical sense. You're not resting and healing, you're actually going out and being proactive and trying to heal, like getting massages or acupuncture or yoga or whatever you have to do to get those muscles stretched back in. (A-36)

I really believe that I'm a vessel. Because I never seem to carry the ball. But I get the ideas and I share them freely. So I'm going to tell you what would really be such an advantage. If the cancer clinics had a program for breast cancer survivors to come and hang out in a sewing class and we could make clothes. And it would be terrific, it would be all volunteer. It would be terrific for all kinds of things, productivity, camaraderie. You'd have an arena to talk openly, "So did you find wearing black leggings helped or did stockings work better?" "You know I found a shop down on 14<sup>th</sup> street that's really helpful". (B-331)

Women expressed a need to be able to use creativity in addressing their clothing needs. Only one woman, who was an accomplished seamstress, had been able to design and redefine clothing patterns for herself to accommodate her new body i.e. shoulder and arm comfort, and to camouflage after-effects of surgery and radiation.

I continued to dress nicely. I made suits but I adapted them. I would do things like cut the sleeves on the bias, making a little more ease. I adapted my shoulder seams. Which was a big advantage over having to go and buy them. (K-144)

Other participants spoke of wanting skills that would help them deal with clothing issues.

For the women who are surviving breast cancer, to give them something productive to do, to give them a chance, to give them a reason to get out of the house, to give them the education on how to dress more appropriately, not inappropriately, with integrity, so that they're not trying to look like the normal person. The people who know about fashion are the experts. There is nothing that will heal you faster than helping someone else heal. (B-340)

### *Support Systems*

As anticipated prior to the study, women have been conditioned, to some extent, to hide their discomfort rather than face ridicule about issues that may be perceived by medical teams as less important to recovery and rehabilitation. Even though women in this study expressed gratitude for strong support systems through diagnosis and treatment, some interactions with treatment teams left the women feeling demoralized. Many researchers (Heim, et al, 1997; Koopman, Hermanson, Diamond, Angell & Spiegel, 1998; Wilmoth, 2001) describe the importance of good support through serious illness, yet fail to mention the effects good “medical” support might have on a patient’s prognosis. Carpenter et al’s (1999) study on self-transformation described a segment of her participants as being “stuck” and there seemed no explanation for why they could not move forward. Some of the factors identified by the participants in Carpenter’s study were lack of courage or strength, lack of clear expectations, and lack of support to make desired changes.

For some BCSs, empathic medical support may be the missing component that allows patients to become “unstuck”, complete the assimilation period successfully, and move on to full integration. Wilmoth (2001) related that women in her study found the degree of information and support lacking from health care providers. Participants in the present study indicated similar experiences.

And this is what happened the other day, I complained again about the lymphedema and the doctor says, “Well B this was just a little cancer. And we got it all. There’s no reason for you not to be back functioning.” It was such a callous, vicious..... She knows nothing about me. She knows nothing about the first surgery. She knows nothing about my partner dying. She knows nothing about me having to crawl to the lawyer’s office because the telephone company wouldn’t listen to me. (B-160)

I will not go to a doctor before I would go to a doctor who is detrimental to your well being. And I even said to her in this kafuffle, “Oh, I get it. You’re not interested in me; you’re interested in the cancer. Well congratulations. You got the cancer. Now I will leave because I need to take care of me and that’s something you don’t get.” And she doesn’t. She was treating the cancer; I can’t fault her for that. But she was not

treating the person at all and I've heard of people being guilty of this before but I've never experienced it first hand. (B-193)

Other participants, struggling with self-acceptance issues, related similar experiences.

The doctors don't seem to understand. A week after my last surgery, I went to see the surgeon and I was not wearing a bra. I didn't think there'd be too many there. I wore a blouse over top and I kept my purse in front of me. And he looked at me and he says, "Oh, I'd better give you a prescription for a prosthesis". I said, "Yes, you can give me the prescription now, but there's no way I'm ready to get it now." It hurts. But he made me feel like, - you look like hell, you need the prosthesis. (L-368)

At the Cross it took me a long time to feel that my doctor felt anything other than a clinical interest in me. I felt very embarrassed to be crying in her presence and almost felt that I had to prove that I was a person worth saving. Truthfully, I was relieved when I did not have to see her. (I-166)

Its not that they [treatment team] have to have sympathy, they had to hear me. (P-262)

So I phoned the Cross Cancer, and they said "I'm sorry it's been a year and a half. You can't come back and talk to him [your oncologist]". Which really pissed me off. I'm sorry, but it did. I had a question so they said you have to go to your family doctor and if she approves of you coming here then you can come back and ask a question. I thought this is the dumbest thing I've ever heard but it happened. (D-44)

Two nurses who participated in this study as BCSs indicated that, although they felt they were supported physically by the medical teams, they did not feel that information relating to their cancer or treatments and care was as forthcoming as it should have been. They both admitted that they were just as fearful and shocked as anyone and they did not feel that being a nurse qualified them as experts about their own breast cancer. These women knew that more information should have been imparted to them so noticed that this element was missing from their hospital stay.

So in terms of patient care, I didn't get much because they knew I knew what to do, right. But that was understandable. But in terms of the medical thing. A lot of times they assumed I knew stuff and I haven't been a nurse in ten years. I forgot most of the stuff I learned. (B-195)

In fact, the first time, nobody talked to me and it could have been that they knew I was a nurse so they thought, “Oh well, she knows everything anyway about it. You don’t have to explain everything”. [I didn’t know everything] Because I mean anytime a disease happens to you, to your own body, you just sort of forget everything because its very frightening and I was 25 years old. I just didn’t find the nurses would approach me for anything. (E-100)

Confirming Ehmann’s (1996) findings, nursing staff working with participants in this study were not seen as valuable sources of information for patients during their recuperative process. Most women are only in the hospital for 24 hours so it may be difficult to get all the information in this short time frame. This again indicates that women who want and need information are not getting it in a timely and empathic manner.

I’m not sure if it was because it was holiday season or understaffing at the hospital, but none of the women who had surgery the same time I did never got instruction on how to do post surgery exercises. One day when I was having a particularly bad time one of the staff ventured in and asked if there was anyone that they could call for me. I would really have appreciated it if someone would have taken the time to sit down and talk to me for a few minutes but that never happened. (I-161)

Most of the nurses, came into my room in 1984 and patted me on the head and said, “You’re our star patient.” Because they didn’t want to talk about it. (P-228)

As in Carpenter et al.’s (1999) study, participants of this study coped best when they were resource rich. Resources in this instance refer to emotional support, physical support, and financial support. The most valuable resource appeared to be financial. Women who did not have sufficient financial resources struggled with procuring adequate alternative treatments not covered under health care. Without adequate medical coverage, participants were unable to secure the types of medication that alleviated side-effects of chemotherapy. They did not have access to exercise facilities such as gyms, and were unable to purchase equipment to use in their own homes.

Single women who were mothers and who were unable to work were unable to pay bills and to provide adequate food for themselves and their families. Coupled with that was the inadequacy of financial resources to secure prostheses and clothing for

comfort and appearance management. In addition to lacking money to address daily essential needs, these women also lacked the supportive relationship of a partner and someone to share the load when physical stamina and time were at a premium.

Because I wasn't covered, I didn't have any... so I had to go on social assistance which was devastating to me. And then to fight for everything you can get, anything you can get. That's been the most difficult cause it doesn't allow you to really heal, does it? You're worried about putting food on the table for your kids. Can't pay this bill this month, can't pay that bill next month. Financially it's been devastating. We're caught without benefits. There was no safety net for me. The other difficult thing was not being able to take care of my child the way I wanted to. (A-78)

You shouldn't have to fight so hard and beg so hard. You shouldn't have to. But you see if money had come when I was sick a year ago, I believe with all my heart I would have been better in six months, because every single month I had to fight to pay my gas, my water, get my food, I'm a single mom. I didn't have time or the ability to take time to heal. (B-154)

Women with financial resources tell a different story.

I didn't have to worry about things and they paid for me to go to a special gym and get in shape and things that get your strength back and I didn't have to rush back to work, so I was really, really lucky all the way along where as I know other people aren't. (F-209)

So I said, "Let's take out some money on our mortgage because we've got so much left. I want windows put in and I want the backyard done. I want some furniture in the living room that I like. If this is going to be my atmosphere and I'm going to die, then I want to enjoy what I have left." (D-206)

It is not helpful to tell a woman that she should be back functioning when she has no financial resources to facilitate that functioning. As indicated by Carpenter et al. (1999) the social constraints that make a survivor feel unsupported, misunderstood, or alienated when seeking support decrease her ability to move forward in the assimilation process.

### *Clothing*

Understanding the every day motives of dressing for the BCS is important in order to adequately assess the full impact of physical, psychological, and social comfort found in clothing choices. Most participants in this study wanted to look good, feel comfortable, and carry on with activities that were pleasurable and meaningful. Appearance related concerns as identified by White (2000) and Bredin (1999), and absence of somatic concerns and optimum physiological functioning as identified by Wyatt & Friedman (1996), were important to participants.

Basically I don't know in my life how big of an issue clothing was, but I think we need to look reasonable for other people. And it's the comfort issue but I'm glad you're doing this study because you're making people aware of it. (J-305).

In this simple statement, this participant incorporated the three key concepts of my concern with the lack of clothing information available to BCS's pre and post treatment: appearance aesthetics, clothing comfort, and body image. Although she implied that clothing wasn't a big issue for her, she wanted to look reasonable. By looking "reasonable", her inference in context was that she wanted to appear symmetrical and her narrative was centred on how she used clothing and the prosthesis to alter her appearance and camouflage her surgery. She also indicated that what she wears was dictated by comfort concerns. Her comfort concerns centred around her physical comfort while wearing the prosthesis and clothes, the psychological comfort she felt knowing she could not be identified as a BCS, and the psychological discomfort she assumed other people would feel if she was not wearing her prosthesis.

After treatment, providing there was sufficient time for women to adjust gradually to physical, psychological, and social changes, the participants moved forward with a deeper understanding of self. If there had been positive support and interaction through the survival and assimilation phases, true integration began and women started to relax and come to terms with a changed body. Through the journaling, I was able to identify that women who have been treated for breast cancer think about clothing, clothing options, and body image much more frequently than

indicated in the personal interviews. Journaling allowed a glimpse into the daily thought processes of some of the participants. It gave me an opportunity to understand the convergence between thinking and doing as they explored the essence of body image and how that was conveyed by daily clothing choices.

It all works without much thought unless something unusual comes up, like shopping for clothes or having company come and stay, or occasions when the comfort clothes won't work like when I went to Hawaii last year. My son is bringing his girlfriend home to live with us in December and I know I will feel odd about having her see me without the prosthesis. (J-J10)

Although all participants were aware that clothing was the impetus of this research study, they were allowed to integrate the clothing experience as it related to their personal story at whatever point they chose. Only two women needed to be asked probing questions about clothing; otherwise excerpts relating to the meaning of clothing emerged spontaneously during the interview process.

- (P) – And then one of the girls' boyfriends wanted to come and see her and she said, "You can't come in the house because my mother has no clothes on. So just ring the doorbell." I wasn't able to put the clothes on that I wore before surgery. The [reconstructed] breast itself was so incredibly painful that I walked around holding my shirt away from my chest. Then I decided I can't do this all the time. So I took a nighty, cut the strap off one side, cut the whole front away and just had this shoulder left in and that's what I wore in the house. So nobody was allowed in. (256, 284) (20 years – lumpectomy and reconstruction; 3 years mastectomy same breast)
- – I was always a fashion plate. I always loved my clothes and I always adored style. I was able to buy stuff. After my mastectomy it was really difficult because, I guess, I still get tinges of that. Where as I go "What an adorable little spaghetti strap dress." Well I can't wear it. (104) (1 ½ years double mastectomy)
- (B) – And if I ever get the opportunity to be a 100 and look back, my boobs came off at the right time because I'm done with them. The only problem I have is with the clothes. (16) (1 year double mastectomy)
- (C) – My clothing choices are very little when I go out at this point. I do house shopping, but clothing shopping, it just depresses me. It's well like I can't wear that. So when I go out, can't have this, can't have that, so my choices were very small. (362) (3 years single mastectomy)



- (D) – My hope was that I could link up with some people who had some ideas on how to dress to camouflage or dress to be comfortable. (160) (2 years single mastectomy)
- (E) – I don't have a lot of problem with clothes because I'm pretty well numb everywhere [from MS] except for [motions to the neck] from there up (171) (18 years lumpectomy, 5 years double mastectomy)
- (F) – I wish I could wear just a regular bathing suit, I wish I could wear a low cut evening dress, I wish I could wear a nice nightgown to bed that looked kind of nice and didn't look lopsided. I guess one thing I could do is have surgery and then I wouldn't have that problem at bed time. (278) (3 years single mastectomy)
- (G) – My sister saw your article and she said "You have to phone this lady." She's been with me when I've gone shopping and seen the frustration sometimes when I wanted to get something and... Maybe this will help some other women. (151) (5 years single mastectomy, 3 years double mastectomy)
- (H) – Well today you can't buy anything – the style of clothing they are even forcing on the young people to wear – spandex – well its impossible for women with breast cancer and you know, having a shape [problem]. (61,65) (17 years lumpectomy)
- (I)– It was also great that it was January and not June, so bulky sweaters covered up my lopsided chest. Scarves were also wonderful accessories. Out on walks when my arm got tired I could discreetly slip my lower arm into the sling and keep on going. (22) (2 years lumpectomy)
- (J) – In the winter there's no big deal because if you're just going out for walks you don't have to wear your prosthesis cause you've got your coat on and your sweatshirt. It would be during the summer when you want to dress cool and because when you're even wearing your sports bra with your prosthesis in the summer, it's not as cool as if you're not wearing one. That's the main issue. What do you do with that, and that's why I'm kind of thinking I have this one casual, cool dress and I should just put a pocket in the inside of it. (261) (3 years single mastectomy)
- (K) – My wardrobe didn't change in character, I just had to go make some new clothes a bit bigger through the breasts and I found jackets.(130) (20 years single mastectomy)
- (L) – [I considered myself a big breasted woman] and of course not having anything decent to wear after the mastectomy, the right breast just started hanging because of its weight and everything else. (50) (3 years single mastectomy, 4 months prophylactic removal of remaining breast)

Through journaling, women indicated that as time went on, decisions made regarding clothing choices were now ingrained and made on a sub-conscious level.

The journaling process made them realize choices based on appearance and comfort had shifted from their pre-breast cancer options.

The new Sears catalogue came today. Because I'm journaling and being more aware, I realize that I now browse through thinking, "I can't wear that", "that's too low cut", "couldn't wear that with my mastectomy bra", "no sense looking at lingerie", etc. (I-J6)

I believe over the years that as my options decreased I just became satisfied with what I could wear rather than what I would like to wear."(P-J1).

This group of women was unique in that they took the opportunity to participate in a research study about clothing and made a proactive decision to deal with issues that were outstanding for them. Because I was seeing women who were at varying stages of the self-preservation process, I had a better idea of how resignation and complacency could easily set in regarding clothing and how repercussions manifest themselves in discomfort and dissatisfaction with appearance.

### *Comfort*

Women spoke about the importance of clothing very early in the survival process when they looked for soft, comfortable clothing immediately after surgery. They used warm, flexible clothing during their chemotherapy treatments and they wanted loose, flowing, lightweight garments during radiation treatments, when skin was raw and tender. In the survival phase, comfort was the predominant theme, with the other two components of camouflage and appearance aesthetics being somewhat less, but still important. However, many times discomfort related back to how uncomfortable they felt in cumbersome prostheses and mastectomy bras that were too tight or were improperly fitted. The very components that were meant to improve their appearance were difficult to wear and made them feel they could not camouflage their disfigurement properly.

Although participants were willing to accept discomfort they thought was temporary, they were more distressed when they realized that discomfort would be chronic. Chronic discomfort exacerbated their problems when attempting to manage appearance related issues. As expected and substantiated by the extensive list of

physical effects of cancer treatment, comfort, the neutral state of physical harmony between a BCS and her environment, had been altered. Every woman interviewed for this study indicated that physical comfort was an issue for her on some level. Garments seldom felt “invisible” and were commonly stated as contributors to stress.

Yesterday was a MISERABLE day, even felt cranky. My clothing hurt my chest and shoulder, everything I tried felt heavy. I know the heat and humidity created swelling but it seemed nothing was LIGHT enough (P-J5)

But with the breast gone, it's the riding up of the bra over the scar is more irritating than hurtful. And it gets caught up there and I have to keep yanking it down. (D-93)

So I wanted to get a good design for a vest, because I felt if I could get a little vest that gathered across here [above the breasts] even in the summer, it would just camouflage enough to make me comfortable. It was my comfort level. (D-121)

As suggested by the literature review, clothing that was binding, tight, or rubbed was difficult to wear and aggravated treatment areas. Clothing comfort and function were important needs to BCSs, yet because they fall outside the medical realm, clothing choices restricted by physical limitations are not considered important to treatment.

Clothing for the immediate post-surgery period was important for women, not only to address camouflage and appearance concerns, but also to meet comfort needs. This was the time women talked about the comfy clothing – sweats and loose clothing. One participant, in a telephone conversation, relayed the feeling that “warm and fuzzy” was what she was looking for because that's how she wanted to feel.

I looked everywhere for post mastectomy outfits to wear. Not anything tight because I was very, very tender. Like a soft camisole that I could have put something light weight in and that wouldn't move around. But there was nothing. I know if it's a problem for me, because its bad enough to get your breast taken out. You come home from the hospital and you have to look lopsided, you hate yourself and what do you do. If you can't wear a bra there's not much you can do. (L-110)

So just mainly comfortable clothing right after the surgery. You're just looking for clothes that are comfy and easy to get on and fit over your drain that's hanging from your hip, and things like that. I was going out shopping so I wore a long coat to hide this drain. (F-160)

And I started to use that [foam breast form] because its very gentle, it can sit on top of the stitches. But I found out afterward that your [remaining] breast can get extremely sore. The left side was sore in another way and didn't want anything on top of itself. It just didn't want any covering or anything there. (K-10)

[After the mastectomy] Actually I looked for comfort clothing a lot – sweats. But I suddenly got into a more relaxed clothing, I seem to remember that. Soft clothing. Sweatshirts and sloppy stuff kind of I guess. (E-237)

Chemotherapy presented challenges for women regarding comfort and clothing choices. Clothing must be chosen that accommodates extra sensitive skin, intravenous lines, and the feeling of being cold. Until hair grew back, keeping the head warm was also an important physiological and physical comfort factor during chemotherapy.

When I was going through chemo I wore really comfortable make-me-feel-good clothes, sweat pants and a favorite shirt, as I was in the bed for hours. (J-J7)

Chemotherapy, just sitting there, comfy elastic pants, just because you're sitting there for a long time. You always have to wear a short sleeve because of the intravenous or whatever. And then just some slip on shoes that you can kick off when you sit in the chair. People get cold there. You get very, very cold sitting there. (F-168)

They also talked about the psychological connection with clothing worn during treatments and feelings associated with those garments.

And I just usually wore this one outfit all the time with this little blouse that did up and everything for my chemo treatments. And after the chemo, I don't like wearing it anymore. It takes you back. (F-172)

After chemotherapy was over, radiation treatments began. Associated with radiation treatment is the intense damage to the skin. Radiation burns were one of the most disturbing and physically damaging effects of treatments to participants in this study. Skin also needed to be protected from the sun's rays, even though many participants indicated that from a comfort perspective, this was one of the most difficult times to keep the radiated area covered. From participant's stories, it appears that skin remains sensitive to UV rays and must continue to be protected from sun exposure long after treatments end.

Women chose various options to meet their clothing needs during radiation. Maternity clothes were a perfect choice as the garments flowed around the torso. They borrowed from friends or visited second hand shops. Because radiation treatments are normally every day for six weeks, planning for short term comfort was not difficult. An issue for some of the women at this time was the fact that they had already purchased a prosthesis and had to accommodate for interaction of the bra and prosthesis on the radiated skin.

Before starting treatments, I had gone to my local second hand store and stocked up on loose shirts. Bras were dispensed in favor of camisoles so that nothing would be rubbing my soon to be tender skin. I was very lucky that I did not get much radiation burn even though I was warned that being fair skinned, I might. I'd like to think that my loose clothes and vigilance with the baby powder helped. (I-42)

Although the women expected to have skin discomfort, they were sometimes surprised at the intensity of the burns.

I would go out to the Cross every day by bus completely covered because I wasn't allowed to get sun and I wasn't allowed this area to get wet or whatever. I had little blisters every where. It was impossible [to put anything next to the skin]. But they never told you what to wear so I got a friend of mine... she didn't use her maternity clothes any longer and I asked if I could borrow them. I wore maternity clothes, tops, during radiation. (P-234)

Although participants were concerned with newer, more form fitting materials like spandex, they generally were able to find suitable clothing that provided some measure of comfort. It was during the assimilation process that it became apparent to them that old wardrobes would no longer work. Although some were saddened at the loss of old clothing systems, some also felt that it was an indication that they were moving forward and had moved past the point where they thought they could go "back to what was".

My wardrobe changed during treatments. Well as soon as you have your surgery it changes. (F-150)

I've been doing this for a month. Its kind of like a garage sale and I can't quite do it. But I'm putting my clothes together. I'm no longer allowing myself to get overwhelmed by how much my clothes don't fit.

I'm trying to separate and just keep the clothes that are comfortable. (B-279)

I held on to them [old wardrobe] for about six to eight months. I thought my skin will be okay and I'll wear this again. So then I just dumped it. There was something about dumping those clothes that was incredibly healing. (P-SI84)

There was a drastic change to my wardrobe. I waited a year but I had to get rid of everything. I gave it away and that was hard to do. (L-206)

The only woman in the study who did not express a significant problem with comfort, suffered from multiple sclerosis (MS) and indicated that she was numb from the neck down. Of all participants, this woman was happiest with her appearance and clothing options. This was corroborated in statements made during the interview and her lack of journaling afterwards. However, even she had problems with the prostheses and bra that her MS numbness could not hide.

I liked doing the journaling but felt I didn't have much to say for relevance sake simply because of MS makes me quite numb. Therefore there is not much about clothing that bothers me. (E-SI6)

I had to get a new bra because I got bigger [prostheses] because I like bigger ones. I never had bigger ones why not get them now. The only thing is that the strap is maybe not thick enough because it's hurting because they're quite heavy. (E-76)

The topic of seasons came up early in the interview process. Although I had originally assumed the cold Alberta winters would be the bigger problem for BCSs, conducting the pilot through a very hot summer where temperatures hovered around 35°C for days, proved to be the more difficult comfort condition. Interviewing the majority of participants in the fall confirmed that hot summers were the more difficult time of year to find comfortable clothing. It was not easy to find clothes that would camouflage, yet allow one to stay cool. Hot summers were definitely the time when comfort compromises were made.

I seem to instinctively work at controlling my own personal environment – wearing clothes that block ALL the sun, keeping my house REALLY, REALLY COLD. I am not sure if I take all these precautions because of not having the proper clothing or if my priority is just living and being

resourceful. They are not actions I am conscious of but I constantly work the issue and act accordingly. (P-J10)

Summer is the worst, summer is really tough. Because clothing bothers my skin so I try to wear as little as possible. I retain fluid in the summer because of the heat so that adds to discomfort. (P-SI-68)

I had to avoid the sun quite a bit. Which was another problem during the summer because it was a hot summer, you didn't want to cover up. Try finding something that is loose and comfortable that would cover you. They're all spaghetti straps and tank tops and stuff. (C-223)

I can't do up buttons, worth nothing. Well big buttons on cardigans are good. I love cardigans because I'm always cold too, almost always cold. (E-191)

And you have to dress warm. If you're a person like me who can't stand clothes or anything else – its hard. And when you shiver you end up getting a pain in your side. Being cold is what bothers me. (H-111)

Problems with thermo-physiological comfort related more to changing environmental temperatures, along with their bodies having to adjust to the temperature fluctuations brought on by chemically induced menopause. One thermo-physiological comfort factor that had not been anticipated by the participants was the effects of air temperature on the silicone gel in the prosthesis. Removal of insulative layers of the chest wall did not seem to contribute to increased feelings of cold for participants who chose not to wear prostheses. Feeling cold was easily alleviated by layering.

Although women in this study indicated that layering did not contribute to restrictions in movement, concerns were expressed about dressing in layers when there was decreased range of motion in the affected arm and when accommodating for effects of lymphedema. Again, I had not anticipated that lymphedema compression sleeves interacting with other garments would exacerbate sensitivity and soreness.

The compression sleeves are a nightmare with fleece. You get stuck getting into the silly things. So you have to find quilting or some kind of a smooth finish in the arms that you can just slide through. Fortunately I don't feel cold so if I wear a fleece I just kind of drape it over my shoulder. But I always have to get the left arm in first. I just can't bring it around. And if it gets jammed, it jolts the shoulder which in turn jolts the chest. But again you find ways around it. I guess it is a compromise. (P-SI-64)

Women in this study felt that they had to make a choice between comfort and appearance. For at least five women in this study, choosing the comfort option played a significant role in diminishing the physical pain they felt from the after-effects of treatments. After trial and error, it was not a difficult choice to embrace.

### *Camouflage*

In nature, plants and animals use camouflage to blend into their surroundings for protection. In this study it seemed to be a vital component of self-preservation.

A group of us used to get together; we were all people who had had cancer. And probably one of the things that would come out of that was we felt people were kind of expecting us to sort of die. Society expects you to die when you have cancer. Fear is fear and people are frightened. And this creates a barrier, and there is no getting through. So someone loses and it's usually the person who they perceive has the problem. So clothing is important. Camouflage is important and that's what clothing is... camouflage. (P- SI-118).

On a psychological level for some of the women in this study, camouflage was a method used for "self"-preservation and became a vital component in helping them come to terms with the changes they experienced. Camouflage was used very early in the breast cancer experience for some women. For others, it was something that evolved out of personal or professional need. Women wanted to relay their inner strength, as well as disguise the fact that they were dealing with a possibly fatal disease.

I felt a strong need to look normal in public for myself and so other people would treat me as the strong and capable person I was and not as someone sick or fragile. Yes, I was dealing with cancer, but no, I was not sick. (J-J1)

When I put on my bra and blouse and makeup and all the other things that make up my public face, I want to go out in to the world and not be reminded that having had cancer is a part of who I am. (I-77)

Camouflage was used immediately after surgery when covering drains from incisions was a concern. During chemotherapy, when outward effects of treatment were most visible, some sort of head covering was usually worn, and makeup was used to replace lost eyebrows and eyelashes. Cosmetics on the face gave the women color



and disguised the energy-draining effects of the treatment. Camouflage relating to radiation was more of a necessity when dealing with radiation burns, spider veins, and discolorations which made women feel self-conscious. Strategies employed by women in this study to incorporate camouflage into their dressing routine included the use of layers, vests, and loose clothing.

I know at first they say, “Oh vests. Vests were a big thing. After you’ve had your surgery just wear vests. Nobody will notice.” Well you know what, you got tired of vests. And I did go out and buy a whole bunch, figuring this is going to solve my problems. I haven’t put one on for a while. But that was my big thing. Every time I went out I put a vest on. (C-414)

So I find I’m prone to wearing layers so that one layer will camouflage another. (D-90)

One good thing about the cold weather. Everyone is wearing layers and if I need to, can just throw my coat on and head uptown to do errands without worrying about what is or is not showing. (I-J22)

I have all his sweaters. Talk about change of clothes. But the fact is I have all his clothes and he was a big man so these were big clothes. (B-299)

New strengths and realizations developed through the survival period allowed the BCS to look at her situation differently and adjust her expectations through the subsequent stages. During the assimilation stage, women began the adjustment period of negotiating appearance with comfort issues. What they had assumed would be temporary physical inconveniences soon became chronic and enduring. Women continued to work with camouflage and feelings of inadequacy well into the integration stage of the self-preservation process. The best coping mechanism regarding clothing and appearance during the integration phase was to change one’s attitude.

Dressing in the morning the debate is – do I cinch my bra strap tight so that I look “perky” in my sweater, or do I slack off on the straps so that my arm doesn’t get too sore by the end of the day (I-J10)

### *Body Image*

Body image is not only related to physical appearance, but is also a perception of body integrity, wholeness, and normal functioning (Carver, et al., 1998).

I went to his funeral and I was kind of scared because I didn't have clothes. I never go out in public. I mean I function, I do the grocery shopping, I do those things... go meet the teacher, that kind of stuff, I don't socialize, I don't go out anywhere because I feel I look horrible. (B-166)

The surgery wasn't that bad. The worst part was looking at your chest and seeing what had changed. (F-14)

But I'll tell you the first time I saw my chest without my breasts on I just about threw up. Because I was, I don't know why. It's just a strange thing to see. It's totally not normal, but it doesn't bother me now. (E-120)

That is why I so desperately went for a consultation for plastic surgery. It wasn't for the breasts. I don't care what I look like naked. But when I go out and I'm wearing a nice outfit, I want it to look nice. Because I have always been a clothes hound. And he said, "Well I can get you symmetrical for clothes and you know how it will look." But then he started talking about chopping into my stomach. (A-134)

It is a relief to not have anything on, but I can't look at myself. I don't like myself to begin with because of the way I look. I'm very self-conscious of that. I feel ugly. (L-116)

The experience of these participants expressing sadness at the loss of the feminine form rather than the breast is corroborated by Wilmoth (2001). To lose the breast meant for some that the "cancer" was gone. No where in the literature on body image after breast cancer was it suggested that the essence of the image was what mattered most. Women knew that there was a choice that had to be made, and that choice was "life". While some participants expressed sadness at the loss of the breast, other women flatly stated that the breast(s) were not missed. When other participants were asked about the validity of this statement, it was suggested that this is a way to cope and that this acceptance softens the loss.

No, I am proud I survived. Look at me. This [being breastless] is my badge of honour. Oh I am proud. My kids tell me all the time, "You be

proud mom.” No, no, no I don’t mind going breastless for that reason. I want people to know that its just boobs man, its nothing. (B-349)

I think the comment, “I don’t really care if I only have one breast, it doesn’t bother me”. It’s a coping mechanism. My Reach to Recovery lady said that even years later she is still hit with the tears and that was normal. We all deal with the emotional stuff in our own ways. (J-J16)

Both of the women in this study who had double mastectomies and chose to wear prostheses expressed relief that they could now get larger breasts (for the small-breasted woman) or smaller breasts (for the large-breasted woman) in the form of prostheses of their choice.

Finding a comfort level with self and body was an important part of integrating the cancer experience into the lived experience. Women in this study were at a loss to integrate their changed shape and image and fitting those changes to clothing that accentuated their positive features. Self-esteem was sometimes low and they had lost the ability to objectively judge whether or not their appearance was acceptable. Often in the interviews, participants would make comments which seemed to indicate that they needed confirmation from some outside source (the researcher) that they looked good and were attractively dressed.

I think they make a mistake sometimes glamorizing these actresses over 50. That is not the norm. For a long time I was striving for that instead of accepting and doing the best you can. I just never thought I was into looks as much as I am. It was never that I was beautiful or anything like that. (B-389)

I’ve always been a very proud person. And now some days I feel, well I don’t have any breasts, why should I wear makeup. I look terrible so why bother. (L-130)

Camouflaging with layers and loose clothing was virtually the only clothing strategy employed by women in this study to mask treatment effects. This study indicated that participants wanted direction in how to channel efforts into effective and workable solution to looking and feeling feminine.

More women bemoaned a “paradise lost” more than the actual loss of the breasts. One woman who had no breasts to speak of prior to her mastectomy spoke of cleavage she had never had, yet had envisioned having after reconstructive surgery.

Some women indicated that a changed body made them long for the opportunity to wear clothes that were not available to them before their surgeries and treatments.

And of course all of the cleavage. Now everything is cleavage. So the cleavage teeshirts are out, cleavage dresses, halter tops are out. This is why I sort of wanted to have reconstruction. (A-174)

I think I have a stronger connection to my brain than my body. However, if somebody said right now, "If we took a few brain cells and gave you breasts, which would you want your brain or breasts?" I'd say take a few and give me breasts. I'd like to experience that. I'd like to know what its like to wear something unbuttoned to here or a cute little dress or just that little flaunting bit that would be fun. (D-249)

I wish I could wear a low cut evening gown, and not that I ever wore a really, really low one, nor would I at this age, but something that just kind of came down or that you could unbutton three buttons instead of one. (F-278)

During assimilation, feelings about body image became much more evident to the women as they started to think about their body and clothing in a different way. As suggested in the literature, BCSs no longer received help after treatments were complete (Crooke, 2001; Pozo-Kaderman, et al., 1999). Only the most sensitive in the medical community understood that the problems for BCSs were ongoing and had a serious impact on quality of life.

They're not my war wounds in that I want to say, "I'm a really strong, tough person". It is something that I went through in my life, and I don't think breast reconstruction will necessarily change anything of the way I feel. The only time it would be nice is when you're wearing something without a bra. Like for instance to bed or whatever. (F-284)

As recovery progressed, clothing became more of a long-term issue as the aftermath of treatment was integrated into the BCSs day to day activities. One woman who had had a double mastectomy related her attempts to sew smocks out of bed sheets because she couldn't find anything in the stores to accommodate her girth and lymphedema during the very hot summer of 2003.

I went to the Saan store. I was determined (bangs table) to get something to wear. It was hot, I was uncomfortable, nothing fit. I know they have plus size and nothing fit. Anything that was plus sized had boobs so I would get this baggy material on top or huge arms or

something. And the same thing with the maternity things. It only exacerbated my problem, it made me look like an old woman who was pregnant, people looked at me weird. (B-287)

Shopping was a particularly difficult experience. Participants indicated it was a traumatic time when they were forced to look at themselves critically as they attempted to fit their changed body into clothes but had no idea what styles would work for their particular situation.

I practically went straight from the doctor's office [after the surgery report] to the shopping mall. There in the change room I sweated and struggled and almost succumbed to tears as I tried to find a sexy nightie or bra that I could wear to cover up my disfigurement. (I-17)

And trying on clothes. It's a very lonely experience. I can't tell you how many times I have gone to buy clothes, gone, left... I'm going to do it today (bangs the table). I'm going to get... and I'm going to buy it and that's that. And half an hour into the store, I'm ready to bawl, and I'm bawling my eyes out and I'm embarrassed and humiliated and everything I've tried on doesn't fit, nothing fits, nothing works. And that day in August, I got mad. I wasn't mad at anybody in particular, I was just mad. (B-325)

And what do you say to people, "I can't have this." So do they look at you and think I'm a prude. So you don't go up to everybody and say, "Well I've had cancer and I can't wear that." (C-366)

I was going to wear my blue jean dress today, but changed my mind when I got it part way on. Its one of those pull over the head things and sometimes my arm is just too stiff to get it on or off comfortably. More than once I've felt a sense of panic as if I'm going to be "trapped". Not too bad if it happens at home, but alone in a store dressing room, it can be really scary. (I-J2)

Participants indicated that they used catalogue or internet shopping rather than visiting stores and poorly designed dressing rooms.

I do most of my shopping on the shopping channel and on the internet through Sears. (L-278,282)

Picked up my parcel from Sears... raced home to try on this new camisole. It's alright, very light so it may be good for the summer but doesn't offer very much support. It's a bit pricey too.. don't know if I'll keep it. And the search continues for the perfect underwear. (C-J7)

Decided to keep the camisole from Sears. I know that I'm making a mistake but its slim pickins out there (C-J8)

### *Appearance Aesthetics*

The problems in effectively managing appearance after breast cancer further lower the self-esteem in these vulnerable women. The women in this study viewed clothing as an important feature of their overall recovery and were looking for information about viable options. They were anxious about what to wear and were less confident about appearance. As suggested by Carver et al. (1998), the women in this study perceived themselves as different and they were sometimes more sensitive about how they looked to themselves than how they looked to others.

I like to look nice for myself, but also for my husband. I want him to be proud of me when we go out in public. (I-J29)

I don't think it is about breast cancer as much as about self-esteem and wanting to look chic all the time. (H-J3)

The importance of reimagining after a serious alteration to the body involves appearance aesthetics. A number of women in this study indicated that it was society that dictated that a pleasing presentation was necessary and that they would be judged on physical appearance. They corroborated Lamb's (2001) suggestion that consumers with physical abnormalities are restricted by choices of style and comfortable materials, and encounter extra costs in acquiring suitable attire. It was interesting, on reading and rereading the transcripts, how participants cloaked psychological and physical comfort levels in ambiguous language.

I was so happy to have recovered that I accepted the problem of a weight gain. (K-82)

It's a relief not to have anything on [prostheses], but I can't look at myself. I'm very self-conscious of that. I feel ugly. (L-116)

Maybe [someone should] do a study of women without prostheses and with them wearing their prosthesis and pictures of their bodies. Show them to people and are they viewing us any differently than one way or the other because if I knew nobody cared I'd probably adopt Carole's strength and attitude. Because a lot of times it's a lot more comfortable not wearing a bloody prosthesis. (J-DB-155)

It is quite embarrassing because when I go away [on business trips] I have to share a room with another person. So as soon as I meet that person, I have to tell them don't be shocked when I take off my bra because.... (L-300)

Although women wanted comfort and a pleasing appearance, appearance was always an important consideration and many times took precedence over comfort.

My husband is very against reconstruction. He said I'm a slow healer to begin with so he really didn't want to see me go through that. And in a few years I will probably get reconstruction. I cannot see myself going through life always worried about what to wear. Are they going to stay down or am I going to be doing something and one will be touching my chin? (L-78)

We were staying in a hotel and the [radiation] burn was so bad that I could barely stand any clothes on my skin. I still wore my prosthesis but I would pad it underneath so that it would stay away from my skin with some gauze. (F-100).

On a scale of importance – [on wearing a prosthesis] day to day activities about a 5. For special occasions about a 10. (C-SI-3)

So you can't take your wig off when you've got company. The wig was very uncomfortable and hot but I just got so that I put it on every day and wore it except around the house and then I had a little head scarf. (F-70)

I found during the summer, when I was going through [chemo], I was still wearing the wig. Yes you had issues during the winter because your head is cold. It was worse in the summer because you're hot. The wig itself is hot, especially on hot days. I remember trying to take my boys to the lake to give them something to do, try to do something with them, and you couldn't roast any wieners because it went up like that. So that was not good. To wear a scarf on your head – try doing that in 30 above weather. So there were points, where I went the hell with you and I took it off and I went with nothing. People were looking at me. I thought "Screw you, this is hot". (C-165)

Symbolic interaction theory suggests that the self emerges from interaction of the person with her social environment (Carpenter & Streubert, 1999). Clothing and symbolism of clothing changed for BCSs after treatment. These women now had to interpret their world based on new realities and derive meaning from the messages society was sending them. As Schwandt (1997) noted, the individual is guided from

this interpretation and derived meaning to take action. Through an understanding of *Social Identity Theory*, participants were more distressed about being identified as someone who was perhaps going to die than they were about their physical difference. They concentrated on appearance modification to move closer to an accepted aesthetic standard and away from the group who were devalued because of appearance (Rudd & Lennon, 2001). Appearance management empowered them and gave them a more positive feeling about themselves.

There was a perception among the women in this study that society sees cancer as a disease that does not go away. Some women with aggressive forms of cancer related that their prognosis was not good. By hiding their difference through symmetry and camouflage, they could avoid the stigma of “illness” and subsequent sympathy or differential treatment.

Yep, I mean it's a concern for me just to go back to work and explain what I've been doing for the last two years. Who's going to take a chance on hiring and training a cancer patient? (A-228)

The problem was trying to fill out the pocket and I hate to think I just want to look like everyone else. I would love to stand out for having a great mind or for writing a book but not because I had a health problem. (P-191)

Three women said that losing their hair was more devastating, even though it was only temporary. They felt the hair loss was a more visible indicator that they had had cancer and did not want to be associated with illness.

I'm a private person and I didn't want everybody to know that I had cancer as I was walking down the street. I mean, there are times when people realize you don't have a breast, but for the most part people don't notice that. When you lose your hair everybody knows and that was difficult. I'm doing the wig because people will either think I'm a cancer patient or I have poor taste in wigs. (F-60)

The oncologist, interviewed for this study, indicated that for women in the lower socio-economic strata, the repercussions of being known as a cancer survivor were not good. For more affluent, professional women, it did not seem to be the same problem. More affluent women had many more options available to them regarding their ability to redefine priorities and meet new wants and needs.



I went back to my job to prove that I could do it and then I chose to retire at the end of that year. I thought, I want to do other things. Because my year off I saw a lot of things I wanted to do with my life. So that kind of opened a window. (F-52)

After the second surgery I'd already given up my job and I'd decided that I wasn't going to be able to go back to work. I was really, really weak, it was everything I could do just to maintain each day. It took me a lot longer to get over than the first mastectomy. (G-77)

Because we are not restricted to one identity, BCSs find that they struggle for both comfort and a pleasing appearance. Women wanted to find acceptable clothing for work that camouflaged their disability. They also wanted to find clothing that met comfort and aesthetic needs for dressier occasions and also for more relaxed, carefree times like holidays and travel. As predicted by Goldsberry et al. (1996) and evidenced by the changes in lifestyle generally for women between the ages of 40-60, the women interviewed were more likely to travel because of retirement or because once they were no longer working, they could travel with partners. They were becoming more involved in leisure activities and used recreation facilities and programs more frequently to accommodate their healing process. On all levels, they strove to meet changing needs.

During the summer when I was working in the greenhouse, the ladies had mentioned they don't wear bras and I said, "I've had surgery." And one lady said, "Well it doesn't matter. You've got your apron on." And it was quite warm so basically I tried initially stuffing my pocket with plastic bag and then that would rattle. And then I stuffed it with a piece of foam, but it felt different, almost heavier. (J-129)

I guess that's why it's been so hard for me because clothes were never part of my identity. I was always a comfort person. I've always dressed according to karma, like my mood that day, what I needed to do. (B-291)

I quickly decided that going lopsided in the pool was a better solution than having to keep an eye out for UFO's (unexpected floating objects). It is not a good feeling when you are reaching and stretching and suddenly you feel something start to pop up from down under. (I-68)

We were in San Francisco for my parent's 80<sup>th</sup> birthday party. No problems with clothing. I found I wore my prosthesis a lot more on the trip than I do at home. I had it on from the time I got dressed until I

went to bed and felt comfortable. Why the difference? Maybe the climate, humidity, around more people all day, on the go and didn't have time to change as much? (J-14)

An apparent conflict for participants in this study was that concern for appearance was vain and shallow. This was demonstrated in comments that alternated between being concerned about how they looked and saying it was not important how they looked.

And the truth is that asking for something like lingerie after coming through a life threatening disease seems very petty. But damn it anyway, if I'm going to live – I'm going to fully live! (I-83)

I'm looking more for the visual. Isn't that shallow? My reputation was always based on "What's she going to wear this time?" And when I was younger, it could be outrageous. It could be whatever I was feeling. (A-146)

I believe that if I was clothes conscious I would find this problem quite depressing. (P-J2)

However, during the interview this participant indicated many times that she was very clothes conscious.

This style with a pocket this side so that its not obvious that I'm without a bra. So I order five of them. They're all the same color. So I've got most of my shirts that are three and four the same. If I find something that fits I really don't care. So loose, sloppy, comfortable.(P-161)

So the clothes, well I don't mind looking like I'm wearing baggy clothes, I really don't want to look like I put my shirt on backwards. And it even looks like the buttons are buttoned the wrong way, like I've missed a buttonhole somewhere, so I guess I've some little pride maybe. So maybe I don't end at the neck after all. (P-165)

This participant's closet was filled with shirts that would accommodate her need for camouflage and comfort (Figure 4). Many times her comments about lack of concern for body image and appearance did not fit with her comments about her wardrobe. Women expressed interest in being able to control the outcome of their appearance yet indicated they lacked the objectivity to accept that



**Figure 4. Shirt Closet of participant “P” displaying a variety of cotton shirts with left pockets**

outcome. For instance, one of the participants who was small breasted was encouraged many years earlier to have reconstruction. As a breast cancer survivor, she was cognizant of the fact that she was even more “imperfect” than before.

I remember going to a doctor [many years ago] and he looked at me and said “You don’t have to be flat-chested.” He said that to me. “I’m going to send you to a plastic surgeon, he’s going to give you breasts”. So I went and he was very outspoken. “You’re just the kind of women because you’re not doing it for your husband.” This is the kind of thing we women face in this society. (D-245)

A pronounced element of this study was the feelings the women had that they must now accept “frumpy”, “matronly”, “old lady”, and “worn by my Mom” clothing to meet their comfort needs.

On Oprah today “Bringing out your inner sexpot.” It made me cringe when they said something about giving up your “Granny underwear” and shopping for sexy lingerie. If anyone needs help feeling sexy, surely it’s a breast cancer survivor. Yet all I’ve seen out there for undergarments definitely falls into the “granny” category. (I-J12)

Bras and saggy breasts are my number one concern. It’s getting to be more of a problem because the clothes just don’t fit. Whether my body

is changing normally. I'm not wanting to be dressed like an old lady yet. I like wild outfits too. (H-141)

It seems to me there are two styles of clothes out there – one for the junior trend setters and the other one for the elderly lady. The polyester shirts with the flowers. I'm thinking, I don't want that. And you know if I want to get a loose fitting blouse, that's what it looks like. My mom would have worn that. (C-422)

They had a fair selection of bathing suits and I'm not young but a lot of them were old lady bathing suits. Maybe somebody else seeing me on the street would say, "You are an old lady." But I'm thinking, those are still too old lady for me. The bras are very boring. They're kind of like "old lady". I want pink, I want green. (F-224)

The participants did not feel that clothing was aesthetically pleasing and felt pushed into styles that did not fit with how they saw themselves. As suggested prior to the research, having to choose garments that were not appealing pre-treatment left women demoralized and critical of their appearance. Through the journaling process, participants made it evident that they struggled to meet the pre-treatment standard for self-image. Positive feelings were decreased, exacerbated by the changed body and inability to appear attractively clothed.

The psychologist, he has been a blessing. He's got me totally understood and I agree with him that I have a real problem between my self-image and my body-image. My self-image is still quite fine frankly because it's not about my body. I get that, okay. The thing is I look in the mirror and I can really feel sick to my stomach at what I see and that's so not who I am. (B-P179)

### *Symmetry*

Symmetry, in the case of the BCS, refers to returning the chest wall to its former balance after surgery through the use of prostheses or through reconstruction. The desire for symmetry is not well understood, yet it is encouraged and reinforced early in the breast cancer process. In the past, volunteer breast cancer survivors presented information on prostheses and mastectomy bras during pre-operative visits with new patients. They brought "fluffies" to stuff the empty side of the bra after surgery so that a woman would be comfortable with her changed shape as soon as possible. This "fluffy" would return the women to "normal" until they were able to be

properly fitted with the prostheses and mastectomy bras approximately three months after surgery. Many women want this information, but it needs to be delivered in a way that allows them to make unbiased, informed decisions. For instance, is there adequate time to grieve for the missing body part(s) and changed body image? Women in this study, who chose to wear prostheses, waited approximately five months to have their prescriptions filled. As evidenced by the self-preservation model (Figure 3), feedback is important to how individuals perceive acceptance of their difference and how willing they are to embrace and give importance to symmetry.

I almost always wear the prosthesis when I think I am going to be in situations to meet people out of the house. When people unexpectedly come to the house, I often cross my arms in front of my chest. (J-18)

I've had a couple of people when I haven't had a bra on kind of feel a bit squeechy. People are still frightened of cancer. They don't want to get it. (D-122)

Many women were self-conscious about having others see them with their prosthesis off. Although they indicated that they admired a woman who had the courage to go out in public with an asymmetrical torso, some women in my study indicated to do that was outside their comfort zone. Two participants, who normally wear prostheses, related stories of going without a prosthesis in public and having other women come up to speak to them about their cancer experience and talk about fears and concerns they were having with a recent diagnosis or problems they were experiencing. The participants indicated how moved they were to be able to offer information and support. It would be interesting to know how many women who are identifiably BCSs are approached in this manner.

Women who have lost both breasts and chose not to wear prostheses at least have basic symmetry. However, they still struggle with fitting clothes that are designed for women with breasts.

I wanted to get a dress and I tried on about five of them and every single one of them was like this (pulls her shirt out from her chest) and I said to my husband, "Even if I'd been trying these dresses on when I did have breasts, they probably wouldn't have fit either." (G-103)

One woman who had a double mastectomy asked me if I knew where there was a good shop for gay men, for they dressed rather fashionably yet didn't have to worry about cleavage and darts. Fitting of dresses seemed to be a common complaint. Shirts, sweaters, blouses, and vests were preferred and more easily accommodated a flat torso with little or no adjustment.

For the women in this study who have had a single mastectomy, going without the prosthesis was a more difficult option to embrace because of the asymmetry. Even if they choose not to wear a bra and the prosthesis on a casual basis around the house, many of them still choose to wear a bra and prosthesis when they dressed up.

I normally put on the prosthesis when I get dressed in going out clothing and normally take it off shortly after I get home. (J-J4)

It will greatly increase my chances of finding a nice outfit if I don't have to worry about the radiation scarring. (F-J2)

But I don't attend functions that mean I have to dress up. (P-171)

I wear my prosthesis when I'm dressing up. If I'm going to a wedding, if I feel like I'm going to go out in public, dressed up I will wear it. Some of my clothes, this will be for when I'm not going to wear it, this will be for when I do wear it. I choose clothes based on whether I'm going to go braless or not, or prosthesis or not. (C-311)

The large breasted woman who has a single mastectomy has two problems. Based on information from this study, women between the ages of 40 – 60 are experiencing the natural aging of the body. With that comes a loss of firmness of the breast tissue. Women who have had lumpectomies find themselves with a hard, firm breast on the treated side and a naturally aging and sagging breast on the other. These conditions contribute to serious asymmetry problems and it is difficult to find comfortable bras to accommodate such diverse breast sizes.

I go through bras every month just about, I can't wear them for much longer .... Because they fall off the side or they get stretched out from the heaviness of this one [remaining normal breast]. It is quite a difference in the way they sit. So you can't wear shirts, I'd have to take a 20 in a shirt to make sure its loose enough and yet can you imagine that when everything else is a medium 12 or 14 so you don't buy shirts to wear because they gap. (H-79)

Because the comfort and symmetry issues were so pronounced for the one participant who was large breasted, she had her second breast removed prophylactically, feeling this would solve her problems.

Women indicated that, after their treatments, reconstruction did not hold the same appeal post-surgery that it had pre-surgery. Many of them were told that they wouldn't be good candidates anyway, particularly if they suffered from another medical condition or had had intense radiation to the chest area. Most of the women in this study struggled with going through more medical procedures when they had barely healed from the first ones. More than one participant expressed the feeling that they would have the second breast removed to avoid having to go through cancer treatment again before they would use reconstruction as an alternative to regain symmetry.

I went to see about being reconstructed about two months ago and that just sounds too barbaric and hideous that I just can't put myself through it. (A-62)

When one of the doctors was doing an examination he says, "Oh you have a lot of flexibility here. You could do reconstruction if you wanted to. Actually they've left a lot for you". It's a small consideration. By going through all that pain, I'm not sure if I want to do that again. (C-291)

And somebody said, "Well why don't you get your other breast uplifted or something?" Because its hanging down to my knees. And I said, Well every operation I've ever had I've had trouble with so I mean if it isn't working cutting yourself open in one sense, do you want to do it? (H-P22)

It was also noted by some participants that reconstructive surgery was paid for by health care, yet prostheses were not.

So it was very difficult after both breasts were removed to try and find some prostheses that were reasonably priced. It's free when you have your breasts redone in surgery. (E-46)

### ***Prostheses & Mastectomy Bras.***

Approximately three months after surgery, if healing has progressed satisfactorily, BCSs are given a prescription for a prosthesis. They are fitted with a breast form made of silicone gel, designed to mimic the breast(s) lost to disease.

Consequently, the silicone form for a woman who is a size 38D is significantly larger and heavier than for a woman who is a size 36A. The breast form is suspended within a specially designed support bra with heavier straps than normal and a tight fit to prevent the prosthesis from shifting on the body.

Women were unprepared for a breast form that would not stay in place if it was not attached to the chest wall. They were not prepared for the interaction of the prosthesis with the altered skin surface. They did not anticipate that the silicone gel prosthesis would take on the heat of a hot summer day or the chill of a winter evening. Only two women in this study indicated that their prosthesis gave them little if any problem. Only one of these women was comfortable with the mastectomy bra and felt that it was possibly because she was small breasted. The other woman, because she had a tiny frame and was big breasted, chose to use a generic sports bra, the type she had worn for years before her breast cancer. Women indicated that if prostheses were comfortable to wear they would not object to using them.

I had no trouble adjusting to the prosthesis. It wasn't uncomfortable and actually the first day I went to the place to get it and wore my new bra and my new boob home I was quite comfortable. I guess I'm as happy as you can be with one [prosthesis]. (F-182, 194)

[I had a prosthesis the first time] and it was awful. It was hot in the summer time and cold in the winter time and you were constantly adjusting things. (G-87)

Even though it's a small prosthesis I find it uncomfortable at times. When it is hot outside it almost seems to weigh more and it feels uncomfortably warm against my chest. Of course warm weather means going out with less clothing so going without the prosthesis is not an option that I feel comfortable with. I also find that it feels "heavy" on my chest when my arm, chest and shoulder are experiencing those "twinges" that I have told you about. (I-SI-113)

But now I can't really even wear a bra. So if there was a way... even I haven't come up with a way of putting something there that means I could wear a shirt without a pocket. I would still prefer to wear a prosthesis if I had the chance... yes something. (P-203)

I haven't been fitted right there yet [a specialty shop]. I haven't come out with a bra that is comfortable yet. They don't have anything there for me. If I could find a bra wider than this on the sides and maybe with



more support under the arm, with boning or something, so it doesn't fold [into my extra skin] into a long rope. (C-333)

All women who were not wearing a prosthesis indicated that they had purchased them and had tried to wear them for symmetry. Although this was important to them, comfort was more important.

[Wearing a prosthesis the first time] I wanted to look the same as everybody else. But then my husband pointed out, "Haven't you ever noticed how many flat-chested women are around." Until he actually drew attention and then I finally realized that probably it is true. So that way I felt it probably doesn't really matter [that I wear prostheses]. (G-95)

So the prosthesis isn't working. It would be nice, then I wouldn't have to keep my pocket full with Kleenex. (P-56)

Other women, who continued to have significant problems with prosthesis and bra comfort, maintained how important it was to appear normal to others. This is a socio-psychological or social comfort issue and was a measure of how they perceived others around them would be if they did not wear the prosthesis. Participants who wore prostheses indicated that, even when physically uncomfortable, they would wear their bra and prostheses if they knew they would be seeing people in their own homes.

The only real issue relating to cancer is when to wear my prosthesis. When I came home from the craft fair I wanted to take off the prosthesis as there was a phantom tenderness in the chest – the missing breast? But as one of my husband's male friends was coming over for a while I left it on until after he left. It will be good to talk to the other ladies as I wonder if they do what I did or if they would just get comfortable. (J-J12)

Six of the 13 women wore their prostheses all the time. "All the time" meant always in public, usually in the privacy of their homes, and when the discomfort became too much, only then would they take it (them) off.

I managed to get a one hour walk on the treadmill in. Once again I should have taken off my prosthesis as the warmer I get the more rubbing against my chest occurs. I don't change bras – take off my prosthesis and put it back on when I'm finished like I know I should do. (I-J18)

This participant was using a treadmill in the privacy of her own home. In a comment made earlier in her journaling, she said:

It even felt great to get my watch off my wrist when I got home from work today. I should have taken my bra and prosthesis off when I got home from work but I hate being lopsided enough to put up with the discomfort. (I-J14)

It is troubling to me that women are so self-conscious of imperfection that they choose to continue wearing uncomfortable items of apparel in private even when they understand that it is not in their best interest to do so.

Women indicated that they chose clothing based on whether or not it would be worn with the prosthesis. This has significant implications for clothing services for women. It is important to recognize that BCSs are employing different strategies in choosing clothing and making purchases and that those strategies incorporate prostheses.

[Buying clothes is based on] Whether I'm going to go braless or not or prosthesis or not. Because I feel I'm out to here with it. I've never been that way. I feel like some baba. There's a shelf there which I've never had before. (C-315)

Gradually, through time I have developed my comfort zone of clothing that I wear today. With me, the daily question is "When will I put on the prosthesis?" Everything else currently in my wardrobe are clothes I am confident I will feel good in depending on the planned occasion. (J-J10)

Small-breasted women did not have the same problem camouflaging one side of their body beneath layers or loose clothing if they chose not to wear the prosthesis. Yet, for small breasted women who wanted symmetry, this was the first time in their lives they had worn a bra on a continual basis. Even for small-breasted women, the bras are heavier and more cumbersome and uncomfortable than what they were used to wearing. To support the gel breast, the bra must be very tight to ensure that there was adequate support and that it did not shift on the torso. They indicated that the ultra support of a mastectomy bra with prosthesis gave them a profile that was nothing like the profile they had before surgery. Large breasted women who use the prosthesis to maintain symmetry found themselves supporting what one woman termed "a football".

So they finally put me into a sports bra and this big football of a breast that sits in my dresser drawer, it just felt like it was coming out under my arm. I was used to that other breast that part of the breast there, it was down to about 1/2 to 1/3 the size. (P-201)

Sure it looks big because I was always a woman who never wore a padded bra. I was always small, and I just never had one of these. [going without a padded bra] is just a small thing and my clothes fit me better. But if you have these two mountains there now and I feel like I'm out there and I don't like it. (C-319)

The more expensive bras the \$75 bras, well there's support. I just felt like I was being choked to death, too much support. There's a lady here that sells beautiful, expensive bras but then I was way out here and that's so not me. (H-85)

Women found the prostheses extremely uncomfortable and heavy. It is interesting that it is accepted practice to place a heavy, loose object in a pocket on the treated side of a woman's chest. In spite of the nerve, muscle, and tissue damage that may subsequently take months or years to heal completely, the affected side is expected to bear the weight of the prosthesis and no one indicates that this is somehow an abnormal expectation. Participants in this study, if they were large breasted, were expected to be able to support a heavy prosthesis on their affected side whether they were large or small framed. Without exception, prostheses are resting on the area of the chest that has undergone surgery and radiation. The varying air temperatures are relayed to the affected skin surface by the prosthesis and must certainly impact pain sensations. Women talked about strategies employed when addressing these concerns, and also of tolerating the physical discomfort for the benefit of symmetry.

I still wore my prosthesis but I would pad it underneath so that it would stay away from my skin with some gauze. (F-102)

Also, I found that putting a pad underneath the prosthesis. I always wore a prosthesis in a cup inside but I found that a nice thick piece of polar fleece, the thickest one you could get, cut into that shape and just anchored behind the brassiere, anchored behind the prosthesis was very, very soft and it also worked quite well with the skin. (K-20)

Quite often when I was fitted with a brassiere, their idea of a comfortable bra and my idea were a little different, and I got brassieres that were so tight that my back was hurting half an hour after I'd been

fitted. And so this addition to the back of the bra opening was the answer. (K-200)

In this study, all but one of the women indicated that the mastectomy bras were uncomfortable and, for some of them, impossible to wear.

I have two mastectomy bras but I never wear them. Because they're nylon and they're lace and they're bigger and heavier than my sports bra and when I was at the Cross for my initial visit, one of the volunteers she had cancer 20 years ago and she showed me a bra, that you could adapt by taking a piece of tee-shirt material and stitch it this way, so that's basically what I've done. (J-139)

So it [the bra band] folds over [into the extra folds of skin under her arm]. Even this is folding over so it's tight and uncomfortable and I'm always pulling at the bra and I'm always uncomfortable. (C-303)

Because I can't wear the bra so finally they produced these wonderful things at the mastectomy store and all these bras had that lace. My good side couldn't even use that fabric. Finally put on my sports bra and this big football of a breast [after my mastectomy] that sits in my dresser drawer. (P-197)

All others lamented the limited bra styles available to them and the inability of prosthesis providers to develop a bra that was both comfortable and aesthetically pleasing. They were looking for seamless cups and even options for asymmetrical and strapless looks in clothing. They found that summer clothes did not cover the wide strapped mastectomy bras. Although women indicated that they wanted to cover up bras and visible effects of treatment, some women would have liked to wear a spaghetti strapped tank or sundress. The fact that they were now unable to choose clothing that fit personal criteria affected their psychological comfort level regarding options for dressing.

I'd certainly do a seamless bra for god sakes, its 2003. There's no seamless bras on the market for mastectomy. I said, "Do you own this shop?" And she said "No". I said "Who owns this shop?" "Well it's a guy." I said, "A guy? Who does the buying, a guy?" (A-204)

What would be really nice would be a bra that went to the waist with no heavy seams under the arms and then maybe some panties with clips that would hold the bra in place. Then you wouldn't have to worry about them coming up and you could go with a lighter prosthesis. (L-256)

Cost of prostheses was a factor for almost half the women in the study, even though many of them had financial assistance through Aids to Daily Living or private health insurance plans. Although they did not pay directly for prostheses, women expressed dismay that one silicone gel breast could cost approximately \$500.00. One woman related purchasing the prosthesis through a television advertisement that was almost identical to her \$500.00 silicone gel breast, yet cost \$45.00. She did not understand how there could be such a price discrepancy between such similar products

I went the first time and I was just angry with the cost and it was \$65 for not even a bra that was comfortable or attractive, and I said, "You guys are making money off of the backs of women who are suffering. I am appalled." Because I couldn't afford \$60 for a bra. I went without a bra for five months before the Cancer clinic finally gave me \$100 and said, "Go and buy yourself a bra." (A-120)

Participants related many problems with improper prosthesis and mastectomy bra fittings. Body changes after an initial fitting can also make a previously purchased breast form and bra difficult to wear. They found financial allowances for one prosthesis every three years did not adequately cover their needs.

When they first fitted me they gave me an A cup. And it just wasn't comfortable. So then I went in for another fitting because I heard they had come out with a more light weight. It was very heavy and they realized that now I was a B cup. I just wasn't fitting in it properly. So they fitted me with a B cup but that one isn't even fitting me properly either, because its not that light weight and when I wear that particular bra what happens is this side looks normal and this digs in. (C-303)

Another participant expressed dismay that orthotics for shoes were covered on a yearly basis, yet a breast prosthesis was not. She rationalized her feelings that prostheses should be covered on a more regular basis by suggesting that a pleasing appearance was not only a benefit to the woman but also to men. Again there is the perception that society is judging the woman on a standard that implies imperfection is not appreciated.

I think for men, when they visualize and look at women they like to see two of them [breasts] there. So it's for men and women you know. (F-208)

### *Menopause.*

The double hit of breast altering surgery and the onset of chemically induced menopause from chemotherapy created a situational change for BCSs that was “sudden, typically unexpected, and marks the person as somehow different or set apart from peers.” (Norris, et al., 1998, P.2). In their “A grounded theory of reimagining” Norris et al. describe how developmental changes such as puberty and gradual changes that are anticipated and shared experiences contrast to the unforeseen changes brought about by such things as rapid weight gain or loss; amputation or paralysis of body parts; scars from burns, surgery, or trauma, ostomies, surgical reconstructions; and cardiac transplantation. Norris et al. identified reimagining as the basic social process of adjusting to this sudden change in body appearance or function. Coupled with that, in the case of BCSs, is the arrival of menopause for women who have been treated with chemotherapy or had hysterectomies to avoid ovarian cancer, which is tied to some forms of breast cancer.

I think the hardest part was when I went into my menopause at 45. Then the body starts changes and I ended up having bladder surgery and I had infection. Then I ruptured my Achilles tendon and was limping around. I really felt crippled, along with the breast being crippled. It was a bad time, it was a really bad time. (H-20)

Participants in this study were entering the stage of life where natural aging of the body occurs at a more rapid pace. A good proportion of these women expressed relief that menopause had come on so suddenly, sparing them the normal mood swings of fluctuating hormones. But they were distressed with the hot flashes.

Summer's more of a concern. Winter there's always things to wear. You have no problem because everything's high necked unless you're too hot. Because you're going through menopause and all the hot flashes and stuff. I have a very hard time. I guess I do have a hard time in the winter too. What do I wear when I go here? I'm fortunate that my body doesn't really sweat but I still need to be able to take off layers, so that's an issue. That hits more of the population than surgery. (F-270)

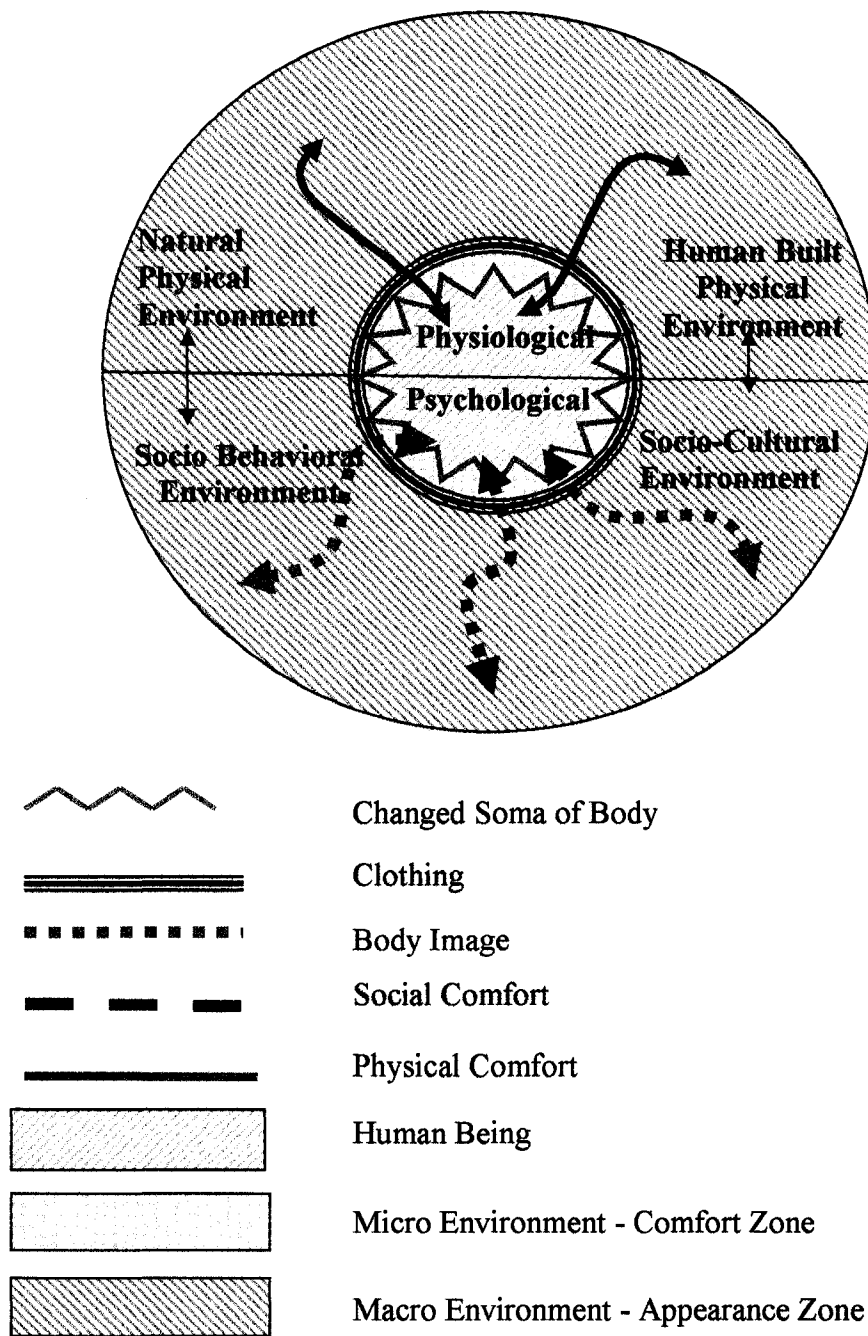
The onset of menopause was more of a psychological transition and brought into clear focus for many that they truly were aging. They saw trendy, fashionable

clothing styles and new fabrics as geared more for the younger woman than the changing body of a woman in mid-life. The seriousness of chemically induced menopause in younger women falls outside the scope of this study, yet has been addressed in a report prepared by the Canadian Breast Cancer Network (CBCN) and the Ontario Breast Cancer Community Research Initiative (OBCCRI) in a national consultation process with young women with breast cancer (OBCCRI, 2003).

### *Clothing as Near Environment after Breast Cancer*

Prior to this study, it was not clear what impact the micro and macro environments might have on the choices of clothing made by BCSs and what interrelationships were actually present (Figure 5). I had assumed physical comfort would be the more desired state after treatment for breast cancer and would take precedence over appearance. This study gives a clearer picture of the interconnectedness between the physiological and psychological human attributes and the environmental interactions associated with each. As expected prior to this study, the micro environment (interaction of clothing with the body) was significantly affected by treatments for breast cancer. Although many of these changes were temporary during the healing period, many others were permanent. The changes to the chest psychologically for the woman. These changes provided the more significant challenge wall were the most damaging physically and to the BCS, when the visibly clothed body interacted with the outside world in the macro environment. Some physiological changes, such as increased sensitivity to UV rays after radiation, dictated that BCSs change how they dressed in the summer.

The more important and meaningful challenge occurred within the human built socio-cultural environment. Consequently, appearance took on even more importance for the majority of the women in this study. Prior to this study, it was not clearly documented that BCSs tolerated a higher level of discomfort to maintain an accepted outer appearance. Within the appearance zone of the macro environment, women who had survived breast cancer worked hard at, and struggled with, attempts to disguise or camouflage the changes to their bodies.



**Figure 5. Clothing as near environment – Post-cancer treatment**

E. Crown, Adapted with permission.

Women spoke not only of their own psychological comfort, but the psychological comfort of others. They felt that people would be uncomfortable in their



presence if their disfigurement was noticeable and many times they felt that they would be shunned if people knew they had had cancer. Even though no one indicated this had happened, their feelings and perceptions of imminent rejection were strongly expressed. In fact the opposite seemed to be true. As a positive outcome of the disease and as part of the experience of growth and insight, friends and acquaintances who were not comfortable with the woman's diagnosis and prognosis quickly fell by the wayside to be replaced by more meaningful personal relationships. Those relationships that persevered grew stronger and deeper. Women spoke of being able to provide support to others once it was known that they were BCSs.

And one night I went to emergency and I didn't wear my prosthesis. And there was this lady who came up to me and asked me about cancer treatment as she said she noticed it. And I encouraged her if she felt there was something strange to go see her doctor. I was not really comfortable [without my prosthesis] but hopefully she did something. (K-123)

One of the things that's been really good about me is that I was able to help them. Offer a lot of support and that was a good thing for me but it was a really good thing for them. Because it was a friend. I didn't have a friend who'd experienced it but they had a friend who they could talk to and I always made myself available and a lot of have said it was really helpful. (F-122)

People back away. They just do and they don't mean to. And they say, "Let's get together." But they never do. (D-129)

Because of the changed soma, clothes no longer felt invisible on the body. This caused a change in the social comfort, physical comfort, and psychological comfort levels for all BCSs. This study supports and adds to Sontag's (1985) findings; women make different choices in dress, clothing, and aesthetics when they know they will be seen by others, even when it is in their own home. They change their approaches to dressing and they bear more physical pain and discomfort if they believe that it will hide the fact they are different.

Each of the participants was asked in the personal interview what her primary concern was relating to clothing as a breast cancer survivor. Eight concerns were expressed by the group of 13 participants. During the debriefing session, the eight attending participants were asked to rank order the concerns expressed by themselves

and others in their cohort. A ranking of 1 meant the concern was most important and a ranking of 8 meant least important. Median ranking appears in brackets after each statement

1. Looking like other women and disguising the fact that I have had breast cancer. (2)
2. Limited clothing choices for breast cancer survivors. (3)
3. Difficulty in finding information and support to help deal with ongoing concerns. (3)
4. Finding comfortable bras and lingerie. (4 )
5. The high emotional cost of being a breast cancer survivor. (4)
6. Finding comfortable prosthesis. (4)
7. The high financial cost of being a breast cancer survivor. (4)
8. Limited choices of attractive lingerie and nightwear for breast cancer survivors. (4)

### *Summary*

Participants in this study indicated that two of their major concerns were appearance and comfort. Clothing and dress are the mediators and moderators that directly affect how BCSs deal with appearance issues and how they accommodate the discomfort of after-effects of treatments. They needed to camouflage effects of treatment and their asymmetry, which meant that clothing strategies used prior to treatment were no longer working for them and they were at a loss about how to do things differently. Many times, they chose to present a pleasing appearance in spite of the discomfort they felt, as it was important to not be seen as someone who was ill. The importance placed on this component of their recovery placed strain on their clothing systems and psyches. Women in this study were concerned about the limited clothing choices available to them as BCSs. Along with their perceptions of limited clothing choice generally, was the complaint that undergarments were not designed to meet ongoing physical limitations, even when the garments were specially designed for BCSs. The women in this study still saw themselves as attractive and alluring and

wanted to display this fact in nicely designed undergarments, lingerie, and nightwear. They were not able to meet the self-concept and body-image standards they had set for themselves, and they lacked information to develop long term strategies to deal with their appearance and comfort on an ongoing basis.

## *Chapter V Conclusions & Implications*

It is important to understand the intrinsic needs of BCSs as they utilize clothing to compliment, conceal, and accentuate the body. Tied to this is a comfort factor which is often taken for granted in the everyday choice of what to wear, yet becomes important when limited by physical factors brought on by cancer treatments. Each woman in this study, like Ehrenreich (2002) and Friedeberger (1996), shared personal stories of attempting to be normal by hiding and camouflaging, and covering the internal and external scars through appearance management and clothing. Although many of the sentiments and statements expressed by participants fall outside the scope of this study, they provide evidence that clothing and comfort issues are major concerns after breast cancer treatment.

Following is an evaluation of methods used for this study and a discussion of the findings regarding each of the study's objectives. Conclusions related to each objective are also provided along with implications for practice and suggestions for further research are then presented.

### *Evaluation of Methods*

My experience was similar to that of Crooks (2001). At almost every interview, there was barely time to settle into a chair and set up the tape recorder before the women began relating their story. Many of the women needed to vocalize their experiences and were open and frank with me. There were emotional moments with tears, even 17 years after the breast cancer treatments. In interview situations, participants were only dealing with what immediately came to mind or topics that were of primary importance to them. Although interviews provided an overview of the whole breast cancer experience, participants were asked to include clothing and comfort issues in their journaling. In wellness, we automatically reach into the closet and put on the clothes that are comfortable, aesthetically pleasing, and represent the image we wish to portray. Journaling was an excellent way to delve into problems and concerns which occurred on a daily basis for BCSs. Through journaling, the thoughts, feelings, and actions surrounding clothing and comfort issues were described.

Although these issues were important to the BCS, they were taken for granted and were not mentioned during the personal interview. The journals revealed how often those automatic actions of clothing choice were disrupted by the reality of meeting their “breast cancer” needs. They described their daily challenges to meet comfort and appearance goals and their strategies to get through those challenges.

There was a direct correlation between the amount of typed, transcribed material from the primary interview and the amount of journaling done by participants. Those who did little journaling had already resolved a lot of their clothing and comfort issues. Comments made during the interview regarding clothing and comfort validated this lack of journaling. Generally, journals contained more information on clothing, comfort, and body image issues than did the personal interviews. Perhaps participants became more aware of their “unconscious” clothing decisions through the interview process and journaling.

Use of the internet was an important component of this study. This was a wonderful way to maintain continual contact, yet remain at arms length, with the participants. It was an opportunity to continue dialoguing when questions arose from the journal submissions. If electronic submissions are employed in future studies, it may be advantageous to explore each person’s computer and internet user patterns at the outset and then design a protocol that met the needs of all participants in a more consistent manner. Even though ten participants agreed to email journal entries, during the study some of them admitted that they were not frequent computer users, were using computers in children’s rooms, or did not use email services regularly enough to automatically think about carrying out journaling on a daily basis.

***Objective 1:***

- *Identify problems and issues related to clothing experienced by the BCS after treatment and rehabilitation.*

It is a fair assessment to say that aesthetics and looking good for others is an important consideration for BCSs, as all participants stated that they wanted to look nice, look “normal”, and be neat and clean. Maintaining that image was sometimes a challenge for them. Although many women stated that comfort was a concern, outer

appearance and camouflaging a missing breast took precedence for 62% of participants. The remaining 38% chose comfort over symmetry, but usually because physical restrictions gave them no choice. All women stated that having a symmetrically shaped body would be their first preference. Study participants verified that their personal and intimate relationships with partners were not affected by the loss of a breast(s), yet the attainment of a feminine silhouette was a major concern. They indicated that they would love to have the option of some form of symmetry in the privacy of their own homes, with their partners and at bedtime, when their physical condition became most apparent. Their desire for symmetry was personal and supports other research done on body image and self-concept.

An important issue for many of the women who had been through chemotherapy was the chemical onset of menopause. Although many women welcomed the immediate cessation of hormones and experienced few problems, others found the hot flashes difficult to deal with. They struggled with what to wear that would both conceal their changed body and allow them the option of removing layers when they got too warm. The suddenness of the experience left many of them unaware of how to deal with the changes. It was interesting to hear the problems and insecurities of these women who were going through a major life-altering cycle at the same time as the body shape was so drastically changed. Psychological assistance through the use of normal menopause interventions is warranted.

Participants in this study all clearly indicated that they had not been told there would be so many lingering physical repercussions from treatments for breast cancer. It is not immediately clear why this is so. Almost all of these repercussions affected the participant's comfort and appearance on some level. From a professional and medical perspective, many journals are overflowing with information on the after-effects of breast cancer treatments. Rehabilitation practitioners need to help clients plan and implement strategies to address daily living challenges associated with cancer and its treatment, preparing women for the significant challenges ahead. These strategies are seen as a way to help foster a positive outlook, focusing on remaining abilities, realistic goals, and addressing the woman's potential for future contributions to society (Livneh, 2000).

Exploring and working with components of creativity may be a way to encourage BCSs to identify personal appearance and body image issues and how they might best deal with them. Directing such adaptation skills, which seem to be vital components of the concept of self-preservation, may contribute to increased feelings of self-confidence as these women learn how to deal with problems in an active, constructive, task-related manner. Patients with high psychosocial adaptation tendencies were more capable of accepting the illness and of getting the support they thought they needed (Carver & Harris, 2000). If we have the perception that control is favorable to better psychosocial adaptation and contributes to lower rates of depression in cancer patients, then the concept of being able to control your outer appearance should also be a valid strategy in successfully adapting to cancer survival. All women in this study expressed a concern for finding information on clothing and clothing options after breast cancer. They also expressed an interest in sharing their experiences in adjusting to the loss of a breast(s) and adapting clothing to their changed reality.

So I'm going to tell you what would really be such an advantage. If the cancer clinics had a program for breast cancer survivors to come and hang out in a sewing class and we could make clothes. And it would be terrific, it would be all volunteer. It would be terrific for all kinds of things, productivity, camaraderie. You'd have an arena to talk openly, "So did you find wearing black leggings helped or did stockings work better?" "You know I found a shop down on 14<sup>th</sup> street that's really helpful". (B-331)

***Objective 2:***

- *Identify and develop clothing design criteria for the BCS, including those criteria related to clothing comfort and clothing aesthetics.*

It became evident very early in the study that the prosthesis and undergarments designed to hold the prosthesis were not working for many of the women. Women who had seldom worn a bra pre-treatment found it a necessity post-treatment if the prosthesis was to be worn. Small breasted women were used to wearing bras that were light and substantially different from the mastectomy bras which are heavy, tight, and durable. Women who were considered large breasted and who had always worn a bra, carried an even heavier load with their prosthesis.

All women who chose to wear the prosthesis found it much heavier than the lost breast. Most women indicated that their shoulders and chest area on the treated side were much more sensitive to weight and pressure after treatment. Some of this was attributed to the surgery, and some of the discomfort was related to radiation treatments. Sensitivity and swelling after lymph node removal was an important consideration when choosing clothing and undergarments. The logic in the design of mastectomy bras and prosthesis that place so much weight on this part of the body eludes me. Numbness due to surgery did not preclude any of the participants from feeling the discomfort and pressure from their undergarments, even without the prosthesis. There is also a need to explore how varying air temperatures impact the temperatures of silicone gel breast forms and how this impacts the surface of the surgically altered and radiated skin.

Women indicated that the present terms for the provision of prosthesis by health plans and government services do not meet their needs. They indicated that poor fitting or changes to the body mean that they need to replace the original prosthesis more often than coverage allows. They did not understand how the cost of reconstruction, which is paid by health care, could compare in cost to supplying prostheses on a more regular basis to women who want them. A cost benefit analysis must surely show that the costs of prostheses are considerably less than the cost of reconstructive surgery, with its resultant medical follow ups and complications. Women in this study expressed a desire to have prosthesis and bra fitting services available at the treatment centre so that they could explore these options as soon as possible. They could therefore avoid the energy draining experience of traveling throughout the city for the prosthesis at a time when they are recovering from treatments and were emotionally drained and at their most vulnerable.

In accommodating physical changes to the body brought about by various breast cancer treatments, dressing ease, garment ease, and ability to use garment closures with numb hands and limited range of motion are issues that need to be addressed for some BCSs. Serious lymphedema and loss of range of motion are problems for some women after breast cancer treatments and limit their ability to comfortably put on and secure garments on the upper and lower body. Women related that seasonal dressing was a



challenge although summer was significantly more uncomfortable than winter. Hypersensitivity to the rays of the sun after radiation treatment caused a problem for BCSs, necessitating summer clothes that were aesthetically appealing yet provided enough cover to the chest, arms, and neck.

Design criteria specific for covering the areas of the body affected by breast cancer would include garment line of mastectomy bras and prostheses, but would not give an “old lady” or “frumpy” impression. This could be effectively achieved either through use of light weight yet opaque material, or through the use of pattern and color. Seams were a concern for some women and garments could be sewn in some aesthetically pleasing manner with seams on the exterior of the garment rather than the inside or moved to a different location on the garment. Appearance of symmetry could also be achieved through line and form in clothing designs. Incorporation of design features such as gathering or folds and also seam lines could give the perception of form, while camouflaging treatments of breast cancer. Attractive modifications to necklines would be an important for BCSs attempting to cover high scars, or effects of radiation treatment. An important issue for women in this study was finding dressier clothing that fit well enough to camouflage and yet be comfortable. Most of the women expressed concern with the lack of choice in finding suitable dressy clothing that would work well with the prosthesis.

One wonders if prosthesis manufacturers and specialty shops are aware that some of their customers do not like and cannot wear the products they are supplying? Undergarments specially designed for BCSs were not comfortable or aesthetically pleasing. Few undergarments in the mainstream marketplace appear to have been tested by users. Underwire bras are particularly difficult for BCSs to wear, yet are commonly used in undergarments. Sports bras were a particular favorite of women in this study, yet are not designed to support the prosthesis. Certainly a normal bra will not hold the prosthesis unless modified. Although it appears that prosthesis designers are trying to mimic the size of the amputated breast, physics would dictate that the dead weight of an artificial substance would be quite different than the live weight of a breast. This problem is best addressed by biomedical engineering studies

**Objective 3:**

- *Identify sources of information regarding important clothing criteria for the BCS.*

In spite of the plethora of information services available, women generally in this study were not accessing them. These were intelligent, involved women who took a proactive role in their breast cancer experience. Yet energy levels were low during treatment and they therefore relied on contact with treatment teams for information. On occasion, women in this study related information from years earlier when they had been treated, unaware that changes had taken place. Misinformation is spread and perpetuated because of this and creates a climate of disservice to BCSs.

Although it had been suggested in the literature that breast cancer rehabilitation was begun at diagnosis, it seems that very little information was either imparted to women on how treatment would affect them, or they did not comprehend the information. In a new development in treatment planning, Winnipeg's Dr. Thomas Hack is audio-recording all treatment planning sessions with his patients and giving them the tapes to take home and listen to at their leisure (CCS, 2003). This process also allows patients to share information with other family members or support networks, and to listen to the tapes as many times as is needed to understand the message. This is a positive step in assisting women through a difficult and emotional experience, and is a proactive way for the medical community to show that they understand the trauma produced by a diagnosis of cancer. Women on average are currently spending less than 36 hours in hospital for breast cancer surgery resulting in little contact with nursing staff. Some information is given by staff before radiation regarding the wearing of loose, comfortable, light weight clothing. Realistically, clothing and its related components are not the specialty of the medical staff in contact with BCSs pre and post treatment.

Two areas that should be addressed are the physical, psychological, and financial debilitation of breast cancer for some women. Service providers and participants corroborate that BCSs must be proactive to access any and all information regarding recovery and recuperation. For those BCSs with strong support systems in

place this may be feasible, as these people help with driving, children, chores, information retrieval, decision making, and provide a sounding board for feelings. For those women without a safety net of loving friends and family, finding assistance to help in all of these areas may be more difficult.

Women who tried to access support services were, for the most part, not impressed with them. Only two women found the pre-operative hospital visit by volunteers helpful. Three women had no contact at all with support services pre or post operative. There appears to be no well defined strategy within the breast care consortium that delivers necessary information and services to breast cancer patients in a uniform and consistent manner across the province. The Arts in Medicine program at the Cross Cancer Clinic in Edmonton was mentioned as a beneficial source of support and encouragement, as well as the Look Good Feel Better program. Participants indicated that this program was about “them” and not about the “cancer”. In some instances in this study, women were trying to move past the cancer experience and, although they needed help and assistance in dealing with the long-term effects of treatment, evaded information services within the “cancer” context. They did not want to talk about cancer. They wanted to do something that was not about cancer, yet be able to talk about their cancer experience. This indicates to me that information services must be delivered in a way that circumvents the “negative” context of breast cancer and accentuates the “positives” of moving forward and accessing information.

Clothing the body in what are perceived to be attractive yet comfortable garments might also be another form of appearance modification information that could be introduced as a rehabilitation component for patients. Carver & Harris (2000) believe that by creating a positive, goal directed rehabilitation atmosphere, the patient can focus on goals they can directly control. We see this approach used when women are counseled on the use of makeup and other appearance modifying strategies after treatment. During my interviews I had suggested that information services for women prior to diagnosis might be an option. This suggestion has also been made in the report on information and support needs for young women with breast cancer (OBCCRI, 2003). Both secondary participants interviewed indicated that women would not be receptive and would choose to not face the possibility of diagnosis before the fact.

Interestingly, as the daughter of a breast cancer victim, I have sought out information on breast cancer and my options since my first biopsy in 1974. Other participants in this study also indicated that, with a family history of cancer, they too had explored information prior to diagnosis. In a societal climate that encourages a proactive approach to health care and disease prevention strategies, it would be interesting to explore the possibility of conducting pre-cancer workshops for women which included all the information that that would normally be delivered after diagnosis. Much like sex-education, a clear mind unaffected by adrenalin contributes to a better understanding of facts.

***Objective 4:***

- *Recommendations regarding delivery of clothing related services for the BCS.*

The need to address body image after diagnosis and treatment of breast cancer has led to the development of the mastectomy and lumpectomy options (MALO) body image restoration program in other hospitals (Ehmann, 1996). The location of this service was not identified in the paper. After a pre-surgical MALOCare consultation, a BCS is given a teaching pack with a limited, select group of materials about making informed decisions without overwhelming her with information. Over a four-week time frame, a progressive image and post-surgery clothing options chart guides the patient in clothing choices for the immediate post-operative period. It is evident from this study that women are looking for information regarding image and clothing early in the breast cancer process.

Earlier intervention in body image work using clothing specialists, possibly even at pre-surgery, may be the strategy that is needed to guide women through the phases of Survival and Assimilation, so that they can reach Integration at an earlier stage. Participants in this study indicated that the days and weeks after diagnosis and before treatments began were often the most difficult time for them, as they felt overwhelmed and positive outcomes were hard to envision. As suggested by Carver & Harris (1999), introducing positive, forward-looking programs which address issues of importance to the women early in the breast cancer experience may be extremely

helpful. As Ehmann (1996) discovered in her MALO program, women embraced the opportunity to take control of a small part of a disempowering experience. Women in that instance were very open to, and appreciative of, information on clothing and appearance requirements pre and post-surgery. Adopting a MALO type program in major centres would not be difficult and a pilot of such a concept is warranted. Even though body image issues are addressed by some pre-operative services, they are not presented in relation to appearance management, comfort issues, and clothing strategies, nor are they delivered by clothing and body image specialists, but by medical staff.

Even though much of the clothing on the market has the potential to meet the needs of the BCS, some women have apparently lost the self-confidence necessary to decide what will be comfortable as well as aesthetically appealing. Currently, each individual seems to be using a trial and error approach to finding what works for her. This is what most of us do under a variety of circumstances – weight gains and losses, other medical conditions, or surgeries. Women in this study felt it would be helpful to know before hand what clothing options worked for others. Much like women who are pregnant and have specialized clothing needs, BCSs too have specific, common, and recurring needs. Women in this study indicated that clothing specialists had information on dressing strategies that worked for specific conditions and could help them with choices. With a fully integrated understanding of key issues and problem areas for BCSs, these specialists are in a perfect position to solutions to clothing aesthetic and comfort concerns.

Women in this study discussed how difficult it was to shop for clothes. They also mentioned the limited availability of clothing that is made well. Use of quality fabrics has decreased, as well as the quality of workmanship, and this affects the fit and comfort of garments. Women mentioned vests, jumpers, and layers as options for them. They also mentioned how difficult it was to employ these strategies in the summer, when light weight, airy clothes were desired. They wanted attractive, well cut clothes that were neither designed for the 15 – 25 age groups, nor the older woman. For women on limited incomes, and who have limited physical resources to shop, finding clothing that appealed to the specific comfort and camouflage needs of the BCS

was a challenge. All participants viewed many of the clothes that accommodated their changed body as unsuitable and clothes “their mother would have worn”. This generation comes from the age of “Aquarius”, as one participant put it, and they still see themselves as fashionable and trendy. They also indicated that well trained and empathic staff was an important component of a successful shopping experience.

Women in this study spent approximately \$2,000/year on clothing. Approximately half of the women indicated that they shop by catalogue or use the internet to purchase clothing and that they are quite happy with the results. This allows them to browse at their leisure and to try on garments in the comfort of their own home. They can also take as much time as they want in choosing whether to keep the garments or not. Various internet clothing stores, such as Land’s End, Eddie Bauer, and Mark’s Work Warehouse, have interactive sites that allow women to fit clothes on a three dimensional model built like them. An internet site that offers this service to BCSs would be a solution to meeting specialized needs. A specialty store that deals in a more aesthetically pleasing approach to providing clothing geared to the BCS might also be a viable enterprise.

Not only for BCSs, but for all individuals who may have physical problems or limitations, a number of things need to be addressed when considering the clothes buying patterns of individuals with specific needs such as:

- Fitting rooms that are large enough to accommodate the woman who may have limited range of motion
- Fitting rooms that meet thermo-comfort needs (not too hot nor cold)
- Adequate mirrors to view all angles
- Subdued lighting to dull the effects of shadows on altered skin surfaces
- Adequate assistance from sensitive and knowledgeable staff
- Privacy

Exploring creativity as it relates to appearance management is not a new concept for breast cancer survivors. However, modifying and manipulating clothing has not been addressed in any meaningful manner. Participants indicated that to effectively take a more active role in appearance and comfort issues, they would need educational information on necessary skills to address their concerns. Many of the

women indicated that if they had had some sort of remedial sewing course targeting adjustments that could be made to clothing i.e. bra padding or adjustment of darts, they could have coped better. Women in this study indicated that they are anxious to learn skills and strategies to make the most of their appearance through the use of apparel. Creativity through collaboration could be an effective way for individuals facing similar challenges and situations, such as BCSs, to develop solutions to problems that are not apparent to someone living outside the reality of breast cancer. These outlets for creativity could also empower women to learn how to incorporate individuality and personality into dressing strategies while accommodating new physical comfort needs.

Clothing and fashion experts have the skills to assist women in incorporating clothing design features to accentuate their best physical characteristics. This could be done through fashion and body image classes or workshops to allow participants to enhance their personal strengths. It is recognized that not all BCSs need appearance management and assistance with clothing comfort issues. However, for those who do, accentuating positive physical attributes can contribute to a positive body image and reestablish a healthy self-concept. Development of well thought out fashion planning programs could be delivered through workshops facilitated by clothing and fashion experts who incorporate their knowledge of fashion theory into the experiences of women treated for breast cancer.

### ***Implications & Recommendations for Further Research***

I corroborate Bredin's (1999) finding that the medical community really does not know how to address a woman's changed image after treatment for breast cancer. It is not the nurse's job and it most certainly is not the surgeon's, oncologist's, or doctor's job to assess how to make her more comfortable and how to accept such a profound change to her body and self-image. Recognition of and respect for women who have lost breasts to breast cancer must be incorporated into every day life on a societal level. Until we move the stigma of asymmetry of breast cancer to a more public arena, women will continue to carry the burden of "appearing normal". As some women stated, if they knew the public wouldn't think any less of them, they would not bother to use the prosthesis. They would decide whether to adopt the feminine

silhouette at their own time and choosing. Serious attention must be given to how prevalent is the BCSs self-criticism and how valid their perceptions are of what society classifies as an acceptable physical presentation. An awareness campaign and a study of public perceptions of breast cancer appear to be warranted. As with other disabilities, until breast cancer is publicly acknowledged in an aesthetic context, women will continue to feel “different” or inadequate. When women are encouraged to regain symmetry as quickly as possible, the silent message is that society will find them unacceptable if they do not make the effort.

One of the gaps in understanding issues for BCSs is the fact that after they leave active treatment, no one is really aware of their issues. Although the support group representative interviewed for this research study felt that BCSs had no issues with clothing, she also admitted that they do not have contact with the women unless they attend monthly meetings. As indicated in this study, there are many BCSs who do not participate in support groups or networking opportunities of an informational nature after their experience, and therefore do not have an avenue to express problems. Also, participants in this study stated that finding information after treatment was a difficult experience. As treatment techniques continue to emerge and evolve, continual assessment of issues and concerns are important to ensure that BCSs needs are acknowledged and met. Each new treatment regimen introduces new and unique appearance and comfort issues. Wear trials with garments regularly worn by BCSs are warranted to ascertain which garment attributes to increased or decreased sensation and discomfort for BCSs.

Another area for increased understanding is terminology used when referring to BCSs. As prognoses for recovery from breast cancer improves and women continue to live longer, this may be an appropriate time to rethink terminology used in relation to breast cancer. When we use the word survivor, we narrow our focus and categorize that person based on a single event (9-11 survivor, Holocaust survivor). Although in many contexts, the word survivor is a strong and resilient descriptor, for the BCS it continues to mean “survivor – so far”. Some women have indicated that the term “survivor” is not their preference (Friedeberger, 1996; Ehrenreich, 2002). It has been suggested that the “breast cancer experienced woman” might be a more appropriate



term (M. Gervais Timmer, personal communication, March 2, 2004). Women in this study indicated that at some point, usually when moving into the integration stage, it became important to begin life based on the future, not on the past. To be “experienced” encapsulates the whole chain of events, not just the impetus for that chain of events. As evidenced by the model of the human social process of “self-preservation” (Figure 3) in this study, breast cancer is truly a complete experience and not just a singular incident.

The term “victim”, too, may be a harsh word to describe the breast cancer survivor (M. Hundleby, personal communication March 19, 2004). Although “victim” might have been appropriate when my mother died of breast cancer in 1967, it may not be appropriate now. Today women are encouraged to take an active part in their health and health care; they are given opportunities to participate in planning and decision making regarding their disease and its outcome. Although some needs are still not being met through the health care system, research in this area by medical professionals and the care community is directed at assisting women during the breast cancer process. Consequently, women who develop breast cancer are not necessarily “victims”. As well as a change of words and descriptors in research studies, it is important that research findings be incorporated and developed into action plans so that theory emerging from these studies becomes relevant and contributes to improved services and practice. While maintaining sensitivity towards the women who have contracted this disease, we must be careful that terminology changes are truly for that reason and not merely to sanitize the experience or insulate those outside the reality of breast cancer.

Because participants in this study volunteered to take part, I was working with a group of women who were taking an active role in investigating workable solutions to clothing and comfort problems. It remains to be seen whether in a larger study of breast cancer survivors there would be proportionally as many problems, or whether I only spoke with women who were experiencing unique situations. The overwhelming response to my request for study participants indicates to me that clothing issues for BCSs are an important and worthy area for continued and more complex research. It is reasonable to conclude that adequate resources and support are necessary for the long-term survivor in order for them to find strength in dealing with the difficulties caused

by the cancer experience (Edgar, et al., 2000). One participant stated, when asked if there was a better word than “survivor” to describe a woman who has lived through breast cancer;

Well it’s labeling in a way, but the other term is victim. And it’s probably the word I abominate most of all in the English language. If I have to be called something I glory in the word survivor. But I prefer just the fact that I am. I just am.” (P-SI-46).

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## APPENDICES

## Guiding Questions

- *How did you get information on breast cancer?*
- *Tell me your experience with menopause?*
- *What alternative treatments have you used?*
- *Describe your support systems?*
- *Tell me about your hospital stay?*
- *In what ways are you affected by the seasons?*
- *Tell me about your prosthesis?*
- *Is clothing an issue for the breast cancer survivor?*
- *Tell me about clothing your body?*
- *Do you use dressmakers to alter clothes?*
- *Was there any purging of the wardrobe?*
- *Tell me about your relationship with clothing after your treatments?*
- *Tell me your feelings about clothing in general?*
- *How have you used creativity to address your clothing concerns?*
- *Describe your creative nature.*
- *If you could change one thing about clothing yourself right now, what would that be?*
- *What is your primary concern about clothing yourself as a BCS?*
- *Is there anything else you would like to add?*

**Demographic Information****Clothing the Breast Cancer Survivor: An Exploration of Functional and Aesthetic Concerns**

Name \_\_\_\_\_

Phone # \_\_\_\_\_

Email Address \_\_\_\_\_

Participant Code \_\_\_\_\_

1. *Which age category do you fit into?*40 – 45 46 – 50 51 – 55 56 – 60 2. *What is the highest level of education you completed?*Elementary School Junior High School High School Trade/technical School College University (less than a degree) University Undergraduate degree Graduate School 3. *What is your working experience outside the home?*Presently employed Previously employed full or part time Never employed outside 4. *Which hand do you predominantly use?*Right Left 5. *At what age was your breast cancer diagnosed?*20-30 31-40 41-50 51-60 >60 6. *Has there been a recurrence of breast cancer?*

Yes   
 No

7. Which breast(s) were affected by the cancer?

Right Breast   
 Left Breast   
 Both Breasts

8. Which procedures were used to treat your breast cancer? Please check all that apply

Radiation   
 Hormone Therapy   
 Chemotherapy   
 Surgery   
 Other \_\_\_\_\_

9. How long has it been since your last treatment for breast cancer?

\_\_\_\_\_ months  
 or  
 \_\_\_\_\_ years

10. If surgery was used to treat your breast cancer, please indicate which type of surgery? Please check off all that apply.

Lumpectomy   
 Total Mastectomy   
 Modified Radical Mastectomy   
 Radical Mastectomy   
 Sentinel Node Biopsy   
 Breast reconstruction

11. How would you describe your health at the present time?

Excellent   
 Good   
 Average   
 Below average   
 Poor

12. What is your total yearly family income before taxes?

less than \$10,000   
 \$10,000 – 30,000   
 \$31,000 – 50,000   
 \$51,000 - 69,000   
 > \$70,000

## Appendix C

**Clothing the Breast Cancer Survivor: A Study of functional and aesthetic needs****Consent Form**

Part 1: Researcher Information		
Name of Principal Investigator:	<i>Rochelle Jackson</i>	
Affiliation:	<i>MSc Candidate, Department of Human Ecology, University of Alberta</i>	
Contact Information:	<i>Phone 458-9500</i>	
Name of Supervisors:	<i>Dr. Elizabeth Crown and Professor Linda Capjack</i>	
Affiliation:	<i>Department of Human Ecology, University of Alberta</i>	
Contact Information:	<i>Phone 492-8856(Dr. Crown) and 492-5997 (Prof. Capjack)</i>	
Part 2: Consent of Subject		
	<b>Yes</b>	<b>No</b>
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached information sheet?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss the study?		
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care.		
Has the issue of confidentiality been explained to you and do you understand who will have access to your records/information?		
I agree to have my interviews audio-taped.		
I agree that the data, without my name attached, may be used in a thesis.		
I agree that the data, without my name attached, may be used for future research.		
I agree that the data, without my name attached, may be used for academic research publications and/or educational programming.		
Part 3: Signatures		
This study was explained to me by: _____		
Signature of Research Participant: _____		
Printed Name: _____		
Witness (if available): _____ Printed Name: _____		
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.		
Researcher: _____		
Printed Name: _____ Date _____		
Expenses to be reimbursed to participant : _____		
Location of personal interview: _____		

If you have any concerns, complaints, or questions about consequences, please contact:

Georgie Jarvis, Secretary to the Human Research Ethics Board, 2-14 Agfor Centre, University of Alberta, AB T5G 2P5 Phone 780-492-4931 Fax 780-492-0097

***Clothing the Breast Cancer Survivor***  
***A Study by Rochelle Jackson, MSc. Candidate***

My name is Rochelle Jackson. I am a graduate student doing a study on clothing concerns for breast cancer survivors in conjunction with the Department of Human Ecology, University of Alberta. I hope to find out if the clothing needs of the long-term breast cancer survivor are being met. You are invited to be in this study because you are a breast cancer survivor. We hope you will be interested in sharing your experiences relating to the meaning of clothing after treatment. You may wish to participate in all of these stages, or only a part of them. That is your decision. You are free to leave the study at any time and should not feel pressured by anyone to take part.

I will collect data from women who are at least one year post-treatment through the following stages:

- Recruitment interview.
- One-on-one interviews. Interviews will be audio tape-recorded.
- Electronic or handwritten personal journals to be kept for a six-week period.
- An audio-taped group discussion at the end of the study.

**What will happen?**

**Stage 1:** After you have indicated you are interested in taking part in this study, you will take part in a recruitment interview of approximately one (1) hour with Rochelle. She will outline the study and what will be required of you. If you agree to take part, after reviewing the information notice, you will sign an Informed Consent Form.

**Stage 2:** You will be interviewed one-on-one by Rochelle in a private setting. We expect the interview will last for one and a half to two hours (1½ to 2). You will be asked to respond to a general question that you would have received the previous week. You will be asked to keep a journal for a six-week period, in which we ask you to write daily about your experiences with clothing. You also have the option of submitting these journal entries electronically to an email address that will be provided to you. How often and how long you chronicle is your decision. After two (2) weeks, Rochelle will collect your journal, photocopy it and review your entries. After this review, you are briefly interviewed again to clarify items that are in the journal. If you are willing, Rochelle will also take pictures of unique and creative clothing systems or items designed to address your particular concerns. Pictures taken will be done so in a way that maintains your anonymity.

**Stage 3:** At the end of the interview and journaling period, Rochelle will compile and analyze all the information. All participants are offered an opportunity to participate in a concluding focus group discussion session.

**Stage 4:** At the end of the study, you will be contacted to arrange a time and place to meet with Rochelle and some of your fellow participants. The intent is to confirm that themes and concepts, which have emerged from the interviews and journals, are

