

FEMALE BREAST CANCER SURVIVORS:  
PERCEIVED STRESSORS AND COPING STRATEGIES  
DURING TREATMENT

by

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## ABSTRACT

Breast cancer is a major health concern for Canadian women. Women diagnosed with breast cancer undergo breast cancer treatment, and must deal with the stressors that treatment presents. The present study drew on Lazarus and Folkman's (1984) transactional model to ensure that the meanings of "stress" and "coping" were based on each woman's appraisals. For the purpose of the study, treatment was defined as at least one breast surgery (i.e., lumpectomy or mastectomy), and at least one form of adjuvant therapy (i.e., chemotherapy, radiation therapy, or hormone therapy).

Ten Caucasian women, aged 47 to 74, took place in an audio-taped, semi-structured interview. On average, the interviews were one hour in length. The research question that guided each interview was: "At each stage of breast cancer treatment what was the most salient stressor, and how did the women cope with that stressor?" The interviews were transcribed and analyzed using the constant comparative method (Strauss & Corbin, 1990). Data analysis also included open coding and memo writing.

The findings revealed that, for these women, breast cancer treatment presented a number of stressors, and the women responded by mobilizing predominantly active coping strategies. In addition to a lack of concrete links between stressors and coping strategies, a clear progression in the coping strategies of the women throughout treatment was not apparent. However, the themes indicate that the appraisal processes of the women during treatment were complex and dynamic. Seven themes emerged from the analysis that represented the salient stressors and coping strategies during treatment. The themes included: (a) Dimensions of Time, (b) Physical Effects of Treatment, (c) Being Prepared, (d) Emotionality During Treatment, (e) Support from Others, (f) Thoughts to Self, and (g) Doing for Self.

What each woman appraised as a stressor depended on her unique interaction with her

environment, and the coping strategies she mobilized depended on her view of the world, her coping resources, and her context. An understanding that each woman's appraisal process (i.e., what are stressors) is unique, and that multiple elements contribute to coping is valuable to clinicians working with women undergoing breast cancer treatment.

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*For my mother*

*A breast cancer survivor*

*and a woman of courage and strength.*

## CHAPTER ONE

### INTRODUCTION

Breast cancer has a considerable impact on Canadian women. One in 9 Canadian women may expect to develop breast cancer in their lifetime, making breast cancer the most frequently diagnosed cancer in Canadian women. Each week in Canada, an average of 415 women are diagnosed with breast cancer, and an average of 102 women die from breast cancer (Canadian Cancer Society website, 2006).

A complete diagnosis of breast cancer comes with details of the cancer, specifically: (a) the stage the cancer is in, (b) whether it has hormone receptors, (c) an estimate of aggressiveness, and (d) if it has spread to surrounding tissue (Canadian Cancer Society website, 2006; Love, 2000). Which treatment is best for each patient is based on the characteristics of the cancer.

A diagnosis of breast cancer leads into a consideration of treatment options. Primary treatment for breast cancer is breast surgery and can be either a lumpectomy, where the tumour is removed along with some surrounding tissue, or a mastectomy, where the entire breast is removed. Adjuvant therapies are treatments given in order to increase the chances of a cure, for example, chemotherapy, radiation therapy, or hormone therapy. (Boston & Louw, 1987; Canadian Cancer Society website, 2006; Haber et al., 1995; Love, 2000). As adjuvant therapy, these three treatments may be used alone, or in a variety of combinations. The goal of treatment for breast cancer is to remove all traces of cancer from the body

There is little cohesiveness in the stress and coping literature with respect to breast cancer. Several authors present coping strategies used during the breast cancer experience, but do not present what the women found stressful, or with what they were coping (e.g. Cowley, Heyman, Stanton, & Millner, 2000; Heim, Valack, & Schaffner, 1997; Osowiecki & Compas, 1999; Ray, Lindop, & Gibson, 1982). There is little research that investigates coping as a process over the

course of breast cancer treatment. There is also little research that addresses the entirety of treatment, in other words, including breast surgery and adjuvant therapy. The present study's purpose was to give a more inclusive picture of the stressors encountered during breast cancer treatment, and the coping strategies mobilized, thus addressing a gap in the literature. The question that guided the research was: "At each stage of breast cancer treatment, what was the most salient stressor, and how did the women cope with that stressor?"

In order to answer the research question, the concept of "stress" had to be defined. There is debate in the academic literature as to the definition of "stress," but the dominant one, and the one used for this research is from Lazarus and Folkman's (1984) transactional model of stress and coping. In this theory, "stress" is defined as "a particular relationship between the person and the environment that is being appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p.19). "Coping," according to this theory, refers to the cognitive appraisal the person makes of the situation, and the steps taken to reduce the amount of perceived stress. In this framework, coping is a process that changes as the situation changes, that is, the situation can be re-appraised as time progresses. The idea that the situation can be re-appraised over time fits with breast cancer treatment, as treatment is a process that presents different issues over time.

Consistent with Lazarus and Folkman's (1984) theory, what is stressful for the woman diagnosed with breast cancer depends on the individual in her unique context. The unpleasant side effects of treatments, the threat to life, and disruption to family and work are some of the things women may find stressful (Haber et al., 1995; Spiegel, 1990). Cancer presents a variety of different threats over time, and how a woman copes will depend on which threat she is attending to at the time (Lazarus, 1993). Therefore, coping strategies may also vary over the course of the disease. The variability of what women find stressful, and the subjective nature of "stress,"

suggests the importance of inviting women to express what in particular they found stressful, and how they chose to cope with those stressors.

Breast cancer treatment is a complex process that can span several months, and presents an array of stressors that women must cope with. Quantitative research has used standardized questionnaires to investigate the stress and coping of women with breast cancer. For example, stress has been measured with questionnaires such as the Profile of Mood States, the Symptom Distress Scale, the Standard Checklist-90-Revised, and the SV-POMS (Manning-Walsh, 2004; Montgomery et al., 2003; Roberts & Cox, 1994), whereas coping has been measured with questionnaires such as the Coping Strategies Inventory and the Bernese Coping Modes (Heim et al., 1997; Osowiecki & Compas, 1999). However, there are few studies that place the coping strategies in the context of the stressors (Wengstrom, Haggmark, & Fosberg, 2001). In addition, although much research indicates that women suffer emotionally and psychologically during breast cancer treatment, few studies have investigated the effects of treatment from the perspective of the women themselves (Thomas-MacLean, 2004). Moreover, although qualitative studies have begun to emerge in response to critiques of quantitative approaches, researchers have tended to focus on only one stage of treatment, for example, breast surgery and radiation therapy (Saares & Suominen, 2005; Thomas-MacLean, 2004; Wengstrom et al., 2001).

In order to access the experiences of the participants during the entirety of their breast cancer treatment, I conducted semi-structured interviews. During these interviews, I asked 10 women to recall their most salient stressor at each stage of treatment, and how they coped with that stressor. Because treatment presents a myriad of issues (e.g., numerous visits to the doctor's office/hospital, interacting with doctors, nurses, and technicians, enduring the treatment procedures, the physical side effects of treatment, the effects on relationships), I wondered if it might be difficult for women in the midst of treatment to choose the most salient stressor. I

anticipated that some women might need distance from their treatment in order to be able to reflect upon the experience, and choose the most salient stressors. One year was chosen as a reasonable amount of time, and therefore, the interviews were at least one year post-treatment. I assumed that the women would remember events that were important to them. The findings of the present study offer a deeper understanding of stress and coping during breast cancer treatment for those who have not lived it, and may be useful to clinicians who work with women undergoing breast cancer treatment.

## CHAPTER TWO

### LITERATURE REVIEW

I begin this review by describing the physiology of the normal female breast, and then provide a definition of breast cancer. Next, I discuss how breast cancer is diagnosed, and the treatment options. I then outline the dominant social discourse (i.e., the expectations members of our culture share) with respect to breast cancer. Next, I discuss the meaning the word “stress” has in today’s society. I then outline stress and coping theory, which leads into a discussion of sources of stress and coping strategies for women with breast cancer. To conclude, I discuss the current literature that places coping strategies in the context of the stressors during breast cancer treatment.

#### *Normal Female Breast Physiology*

In this section, I describe the anatomy of the normal female breast so that the impact and treatment of cancer can be understood in context. The following description of a disease-free female breast draws from both the Canadian Cancer Society’s website (2006) and Love (2000).

Breast size varies from individual to individual, and there are no rules for what is a “normal” size. About a third of the breast is composed of fat tissue, and the rest is breast tissue. The amount of breast tissue remains constant, but the amount of fat tissue changes with changes in the woman’s weight. Over her adult lifetime a woman’s breasts naturally change in size depending on her weight.

The breast itself is tear-shaped, with most of the breast tissue lying towards the armpit and upper breast, while the fat rests mainly in the middle and lower parts of the breast. The nipples lie on the exterior of the breast, surrounded by a darker area of skin called the areola. As with the breast itself, the size and shape of the areola varies from woman to woman.

The internal components of the breast parallel the rest of the body and contain arteries (carry oxygen rich blood to the cells), veins (carry oxygen depleted blood away from the cells), and nerves (carry the messages of the nervous system). The breasts also contain part of the lymphatic system (lymphatics), which is a network of vessels that collect waste products collected from the cells and then pass the fluid through lymph nodes that are found in various parts of the body. The lymph nodes act as strainers, filtering out waste and re-cycling the remaining fluid into the bloodstream. The lymph nodes perform an additional function as part of the immune system; they monitor what is in the fluid and if there is anything dangerous they hold onto it and mount an immune response.

#### *Definition of Breast Cancer*

Regardless of where it occurs in the body, cancer is the uncontrolled reproduction of cells (Boston & Louw, 1987). While these cells grow uncontrolled, creating lumps, they also lose any specialized function they may have had, and become parasites. They invade the tissues of the body and demand nutrition at the expense of healthy tissue. As the cancer becomes more advanced metastasis can occur, where “rogue cells” break away from the primary tumor and spread to other areas of the body, establishing new tumors where they settle (Love, 2000). Breast cancer is, therefore, cancer that originates in the breast of either a man or a woman.

#### *Diagnosis of Breast Cancer*

Breast cancer is most often found in one of three ways: (a) when a woman tells her doctor of an unusual lump in the breast or a change in appearance of the breast, (b) when a doctor finds an abnormality upon examining a woman’s breast, or (c) through screening mammography (Canadian Cancer Society website, 2006). In addition, changes in density of the breast, and any discharge from the nipple may indicate cancer (Boston & Louw, 1987). A definitive diagnosis of breast cancer requires a biopsy (Canadian Cancer Society website, 2006).

A biopsy can be done in different ways (e.g., with a fine needle under local anesthetic, or with a thicker needle under ultrasound guidance), but regardless of how it is done, all biopsies result in a cell sample that is sent to a pathologist for inspection (Canadian Cancer Society website, 2006; Haber et al., 1995). If the cells are cancerous, a diagnosis of cancer is made. This initial diagnosis includes some of the characteristics of the cancer, however, a complete diagnosis also includes the stage of the cancer. Sometimes, the stage of the cancer can only be determined after surgery and additional testing (e.g., removal and testing of some lymph nodes) (Canadian Cancer Society website, 2006).

In summary, breast cancer can be initially suspected in a number of ways. A biopsy is needed for a definitive diagnosis of cancer. The initial diagnosis of breast cancer includes some of the characteristics of the cancer, and a complete diagnosis is often not available until after surgery and additional testing.

#### *Characteristics and Stages of Breast Cancer*

Upon receiving a cancerous tissue sample from a biopsy, the pathologist will quantify some of the characteristics of the cancer. The pathologist will estimate the “aggressiveness” of the cancer, which indicates how fast the cancer is likely to spread. Highly aggressive cancers tend to grow and spread more quickly than the less aggressive cancers (Canadian Cancer Society website, 2006). The pathologist looks at various qualities of the cancer cells to estimate aggressiveness. For example, “wild looking” cell nuclei tend to belong to more aggressive cancers, and more aggressive cancers have more actively reproducing cells than less aggressive cancers (Canadian Cancer Society website, 2006; Love, 2000). The pathologist will also test the cancerous cells to find out if they have hormone (either estrogen or progesterone) receptors (Canadian Cancer Society website, 2006). These characteristics of the cancer inform the



oncologist of which treatments are indicated, how aggressive treatment needs to be, and what the chances of survival are for the patient (Haber et al., 1995; Love, 2000).

The oncologist must know the stage of the cancer in order to evaluate treatment options. Oftentimes, the stage of the cancer is not known until after surgery (Canadian Cancer Society website, 2006). The stages of breast cancer range from 1 to 4, and later stages indicate the degree of spread of the cancer from its initial site. A more advanced stage indicates the need for more aggressive treatment. In Stage 1, the cancerous tumor is contained in the breast and is less than 5 cm in diameter. In Stage 2, the cancerous tumor is: (a) small with positive lymph nodes (i.e., cancer is in the lymph nodes), (b) between 2 and 5 cm with positive or negative lymph nodes, or (c) larger than 5 cm with positive lymph nodes. In Stage 3, the tumor is larger than 5 cm, there are lymph nodes involved, and there may be evidence of local advancement (e.g., ulceration of the skin) of the cancer. Finally, in Stage 4, there is evidence of metastasis, or spread of the cancer to other parts of the body (Canadian Cancer Society website, 2006; Boston & Louw, 1987; Love, 2000).

In summary, a complete diagnosis of breast cancer includes an explanation of some of the characteristics of the cancer (e.g., an estimate of aggressiveness), the presence/absence of hormone receptors, and the stage of the cancer. This information indicates to the oncologist which combination of treatments is most likely to result in the patient's surviving breast cancer.

#### *Treatment Options and their Side Effects*

Breast surgery is considered primary treatment for breast cancer, while chemotherapy, radiation therapy, and hormone therapy are considered adjuvant therapies (Canadian Cancer Society website, 2006). Surgery, chemotherapy, radiation therapy, and hormone therapy are all classified as conventional cancer treatments (BC Cancer Agency website, 2006). The Canadian Cancer Society website (2006) provides a description of the different treatments for breast

cancer. Surgery is performed on the breast with the intention of removing the tumor, and can be either a lumpectomy or a mastectomy. In a lumpectomy the tumor is removed with some surrounding healthy tissue, whereas a mastectomy requires the removal of the entire breast. In both cases, lymph nodes are usually removed to check for spreading of the cancer. Adjuvant treatment for breast cancer can consist of chemotherapy, radiation therapy, and/or hormone therapy. Chemotherapy is the use of drugs that interfere with the cancer cells' ability to grow and spread. Radiation therapy is the use of high energy x-rays to destroy cancer cells. Hormone therapy is used when the tumor is sensitive to the hormones estrogen or progesterone. The hormone therapy reduces the availability of these hormones, thus starving the cancer cells and slowing their growth.

All of the conventional treatments for breast cancer have side effects. Breast surgery can result in a variety of physical symptoms, including pain, swelling of the arm (lymphedema), bruising, nerve damage, and fatigue (Love, 2000). In addition to killing the cancer cells, chemotherapy also kills healthy cells, resulting in side effects such as nausea, vomiting, loss of appetite, fatigue, hair loss, and decreased effectiveness of the immune system (Boston & Louw, 1987; Canadian Cancer Society website, 2006; Haber et al., 1995; Love, 2000). Some possible side effects of radiation therapy are skin burn, breast tenderness, and fatigue (Boston & Louw, 1987; Love, 2000). Hormone therapy can have a number of side effects, including hot flashes, gynecological discomfort, depression, and blood clots (Love, 2000).

In summary, conventional treatment for breast cancer can include surgery, chemotherapy, radiation therapy, and hormone therapy. Which treatments the physician recommends depends on the unique characteristics of the particular woman's breast cancer. As the woman progresses through her treatment regime she will face a number of different side effects that depend on

which treatment she is experiencing at that time. Breast cancer treatment is, therefore, a process that presents different side effects over time.

### *Breast Cancer: the Social Context*

Breast cancer is unique among the life-threatening diseases. Whereas in other life-threatening diseases mortality is understood to be the fundamental threat, in breast cancer the discourse focuses on issues such as body image, identity, and self-worth (Thorne & Murray, 2000). Sexuality and femininity are intrinsically linked to breast cancer; in fact, the reality that breast cancer is a potentially fatal disease is often eclipsed by the fact that the women may lose a breast during treatment (Thorne & Murray, 2000). Therefore, when attempting to assess the psychological impact of breast cancer for a woman it is important to be aware of how society views women's breasts. Society's viewpoint likely has some influence on how women perceive their breasts, and consequently what breast cancer may represent to them.

The importance of breasts begins in early adolescence, when girls' breasts begin to develop. Many young girls look forward to their own breast development, and watch the development of other girls' breasts carefully (Zilbach, 1993). As the breasts grow larger they become a part of the girl's female self and contribute to her estimation of her own attractiveness (Zilback, 1993). Breasts become a focal point of femininity and self-esteem. This focus on breasts is assumed to carry into adulthood, when breasts are often linked to femininity and sexuality, and are the most visible and tangible signifier of womanhood in Western culture (Landmark & Wahl, 2002; Langellier & Sullivan, 1998). The media supports the notion of breasts being a valuable asset for a woman. Bodies of women appear everywhere in media images and advertisements, and are used to sell a variety of items (Daniluk, 1998). Part of the powerful message given by the media is that the breasts are one of a woman's most valuable assets (Daniluk, 1998). Therefore, there is an assumption in society that because breast cancer

threatens the breast it must carry feelings of threat to sexuality, femininity, body-image, and self-esteem.

We could expect from the above that maintaining the look of two breasts is important to most women. There is evidence that society prefers that women to maintain the “normal” look of two breasts – Haber et al. (1995) pointed out that discussions of breast surgery between surgeon and patient may include the option of reconstruction, and Thorne and Murray (2000) noted that women “barely recovered from anesthetic” are often encouraged to use prosthetics. There is also evidence provided by Landmark and Wahl (2002) that women with breast cancer want to look like they still have two breasts. These authors interviewed 10 women (ages 39 to 69) with newly diagnosed breast cancer, and no distant metastases. Landmark and Wahl kept their sample criteria open in order to obtain a variation in demographic and clinical characteristics such as age, occupation, and type of cancer. The interview transcripts were analyzed using the main steps in Grounded Theory (Strauss & Corbin, 1990). The authors’ findings revealed that the female breast is linked to femininity and sexuality, and further stated that the desire to hide the loss of a breast was a striking result of their study. Some participants wore scarves, some chose to use a prosthetic breast, and others could not comfortably disguise the loss and chose to hide themselves. These findings support expectations that arise from the social discourse.

The use of interviews meant that the women were able to express in detail their feelings about losing a breast, and the authors presented quotations to support their contention that the women wanted to hide their loss of a breast. However, the quotations used to support their conclusions do not appear to focus on the loss of femininity and degradation, as the authors state. The quotations indicated that losing a breast might have resulted in negative feelings, but that overall, survival was more important to these women. It is possible that the authors interpreted

the women's quotations through a filter of the social discourse, and therefore found what they expected – that losing a breast was an assault on the women's femininity.

Langellier and Sullivan (1998) explored in-depth how women with breast cancer felt about their breasts. These authors used open-ended interviews ranging from 1 to 3 hours to allow participants to tell their own stories about breast cancer. Seventeen women (ages 32 to 64) with a wide range of treatment plans [lumpectomy (7), mastectomy (10), radiation (5), chemotherapy (6), and tamoxifen (4) in various combinations] participated. In their analysis, Langellier and Sullivan focused on "breast talk;" discussion by the participants that was specifically about their breasts. The results of their thematic analysis challenge the dominant idea that all women see breast cancer as an assault on their femininity and sexuality. Four types of meanings applied to breasts were found in the data: the functional breast, the medicalized breast, the gendered breast, and the sexualized breast.

The women spoke about the "functional breast" which was defined by what the breasts do. Some participants spoke of the importance of breasts in breast-feeding. One was happy that she had had the chance to breast-feed her children before a double-mastectomy whereas another lamented having chosen to not breast-feed her children when she could have. Even though she did not plan on having more children she did not like losing the option of breast-feeding due to cancer. Some women spoke of the functional repercussions of losing a breast, the feeling of "lopsidedness" and the need to modify activities that were done with ease before the mastectomy. One woman attributed her back pain to the uneven distribution of weight on her chest due to her mastectomy. Another woman chose to have a second mastectomy, saying that the remaining breast pulled painfully on her mastectomy scar, and that the remaining breast did not "work" (referring to the loss of erotic sensation).

The medicalized breast was described in medical language. Participants spoke of the size of their tumors, whether the tumors had hormone receptors, and the kinds of treatment they experienced. Participants repeated what they were told by the medical professionals and added what they had learned from their own readings, creating a new vocabulary. The medicalized breast did not carry any meanings of femininity or sexuality, as it was thought of as an entity separate from the body. Treatment of the cancer was spoken of in aggressive terms as “an assault on my body” and “an invasion of my body” (Langellier & Sullivan, 1998, p. 7). The issue of losing a breast through a mastectomy became, for some participants, subordinate to survival, while others felt strongly about conserving their breast through a lumpectomy.

The gendered breast encapsulated the struggle some women went through as they weighed breast cancer against the idea of the female breast as a sign of femininity, beauty, and sexuality. Most participants rejected the idea of large breasts as a sign of femininity. Women spoke of being able to wear clothes that either concealed or did not conceal the fact that they had had a mastectomy. The women were aware of the Western cultural norm of femininity, but were not hindered by it. The loss of a breast (or both breasts) and the effect that has on feminine appearance was a non-issue for some, a marginal issue for others, and a manageable issue for others. The more salient issue for the women was to be matched: to have no breasts or to have two breasts. Cultural associations of breasts with femininity were less important than their own body image in terms of wholeness and matching.

The sexualized breast belonged to the women themselves as well as to others, and focused on the intimate experience of “breasted-ness.” Sexuality included the look of the women’s bodies and the feeling of the breast; treatments for breast cancer can change the sensations experienced by the women when their breast is touched. One woman found her breasts afforded her minimal pleasurable sensation compared to before breast cancer. The meaning of the sexual breast was

also different for women who were partnered versus women who were not. One single woman no longer went on dates and was self-conscious about the idea of showing her naked body to a man, while a married woman found that her husband's attitude had an effect on her perception – he said he would rather have her alive than have two natural breasts. Another woman chose to have her mastectomy scar tattooed to give it erotic properties where she felt there were previously none. The sexualized breast carries many different meanings, depending on the woman, and also her life situation.

In summary, despite the assumptions society makes about the meaning breasts have for women, Langellier and Sullivan (1998) found that women ascribe different meanings to their breasts based on what is important to them. Contrary to what the authors stated, the quotations provided in the study by Landmark and Wahl (2002) supported the contention that women value survival, and do not always feel hindered by society's expectations of what it means to lose a breast. The meaning breasts hold for women appears to be personal and may be best accessed through in-depth interviews. When attempting to assess the impact of breast cancer, it is important to be aware of both the social discourse surrounding women's breasts, and the unique meanings breasts hold to each woman.

### *The Stress Discourse*

The word "stress" is familiar to everyone, and is widely used for a variety of things, from describing a state of being (e.g., "I'm stressed") to explaining the cause of something else (e.g., "I got the flu because I was so stressed at work"). Where did the idea of "stress" come from, and why is it such a popular concept?

"Stress" as a concept did not exist before the 19<sup>th</sup> century, either as a set of facts to describe suffering, or as a way of explaining the suffering of loss (Kugelman, 1992). In detailing the historical origins of stress, Kugelman (1992) stated that the notion of stress emerged from the

perceptions surrounding the Second World War. There was interest in the idea of stress before the war, but not the focused interest that was present after. There was no single source of the concept of “stress” – it appeared in various forms in different fields at around the same time: the late 1930s and early 1940s. By the 1950s, studies of stress were beginning to be found in published journals.

Historians of stress describe the research into stress that began at the time of the Second World War as if war was only the impetus for the development of stress as a concept (Kugelman, 1992). Perhaps war was what gave stress its distinctive character that we see in the discourse of stress today (Kugelman, 1992). One question that came out of the Second World War was: how much stress can somebody take before he (the soldier) breaks, and what can be done to extend that? It was an important question when trying to determine how to manage soldiers fighting in the war, but also began the emphasis on attack and defense in the discourse on stress; on the hostile nature of the world around us, and the defensive measures needed to cope with the world. Prior to the Second World War, psychiatry was able to function without worrying about the environment, but with the war the outside world could not be ignored, and it became necessary to find a way to deal with the hostility of the world (Kugelman, 1992). The time frame of events indicates that the concept of “stress” already existed, and the events of the Second World War resulted in individuals focusing on it (Kugelman, 1992).

The difficulty with “stress” is that it is a widespread concept, and one whose definition is highly ambiguous (Newton, 1999). “Stress” is difficult to define but familiar to everyone, and is widely used by lay people as an explanation for certain types of illnesses, despite the fact that the research lacks any conclusive proof of this (Mulhall, 1996; Newton, 1999). The relationship between stress and illness is supported by popular experience; for example, some people claim



they get a headache in “moments of stress” (Newton, 1999). The lack of firm academic support for the idea of stress leads to the question: Why is stress such a popular and widespread subject?

The standard answer is that we believe in stress because we have, in fact, become more stressed than our predecessors (Newton, 1999). The problem with this answer is that there is no way to know if we are indeed more “stressed.” As Newton pointed out, the ability to express “stress” depends on the stress discourse, and the ability to learn the language of stress. Because the language of stress did not exist in the past, there was no way to express it. It could then be argued that stress is not something that occurs naturally, but rather is a product of social science research – basically that research has been amazingly successful at convincing us that stress is an objective fact. This does not explain why the stress discourse has been so much more successful than other social science discourses (Newton, 1999).

The popularity of the current stress representations could be due to three reasons (Newton, 1999). First, stress has been able to fill a gap left by medical science. It has become a way to explain the unexplainable aspects of health, for example, it is often cited as being a main cause of coronary heart disease or cancer. Because stress is subjective, it has the power of never being completely known, while at the same time being everywhere (Newton, 1999). Its subjectivity makes it an appropriate concept to fill the discursive spaces left by the unknown areas in the study of health. In this way, researchers have participated in developing a discourse with a wide application. Second, the stress discourse promotes the idea of an individual as someone who defines both her psychological and physical well being in terms of her ability to cope well with stress. The stress discourse tells us that people who are coping well, who are “stress-fit,” will be promoted in life, whereas those who are not “stress-fit” are likely to suffer poor mental and physical health (Newton, 1999). Implicit in this language of stress is that it is the individual who

has to cope with the complexities of the modern world. Third, the concept of stress provides a “catch-all” for the range of subjective experiences found in the modern world. The stress discourse provides reassurance by explaining how it is normal to feel stressed in certain conditions, and providing strategies to cope.

There is little research concerning lay beliefs of the concept of stress. Some research has found that it is defined as an outside invisible force, others have found it defined as an external force that is internalized, whereas others found it defined as something that builds inside and needs to be released (Mulhall, 1996). Whichever way people choose to define it, it is impossible to avoid the current popular discourse on stress. One example of the stress phenomenon is the abundance of self-help books written by physicians. These books frequently place the responsibility for managing stress on the individual (Mulhall, 1996). For the female breast cancer patient, this stress discourse means the burden is solely on her to manage her stress.

In summary, “stress” is a concept that, although ubiquitous in our society, is poorly understood. There are a variety of definitions to choose from in both the literature and everyday language, meaning that one definition cannot be regularly applied. In addition, “stress” is a subjective concept, and what is stressful for one person may not be stressful for another. This indicates that it is critical to define “stress” when attempting to find out what women with breast cancer find stressful, and suggests that an effective way to identify what women find stressful during breast cancer treatment is to ask them. In the present study, through open-ended interviews, participants had the opportunity to identify their most salient stressor during each stage of treatment.

### *Stress and Coping Theory*

The concept of coping began to “come into its own” during the 1960s and 1970s, along with an increased interest in stress (Lazarus, 1993). The current dominant psychosocial theory of

stress and coping was developed by Lazarus and Folkman (1984), and has been explored in relation to numerous populations, for example, different cultures, minorities, students, women in the workforce, and bereaved caregivers (Aldwin, 1994; Long, 1998; Slavin, Rainer, McCreary, & Gowda, 1991; Stein, Folkman, Trabasso, & Richards, 1997). Lazarus and Folkman's theory has a dominance and universality that make it an appropriate framework to use when exploring stress and coping of women during breast cancer treatment.

The definition of stress given by Lazarus and Folkman is: "Psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p.19). Two key processes mediate the person-environment relationship: cognitive appraisal and coping.

Cognitive appraisal is an evaluative process of categorizing an encounter with respect to the person's well being (Lazarus & Folkman, 1984). As an evaluative process it focuses on meaning or significance and takes place continuously while the person is conscious. There are two forms of cognitive appraisal: primary and secondary (Lazarus & Folkman, 1984). Primary appraisal can be placed into three categories: irrelevant, benign-positive, and stressful. Irrelevant means that the environmental encounter is perceived as having no impact on the person's well being; there is nothing to be lost, gained, or harmed. A benign-positive appraisal means that the outcome of an encounter is judged to be positive for the person's well being. This type of appraisal is characterized by pleasurable emotions (a totally benign-positive appraisal may be rare; there is the possibility that the person may feel some apprehension that the desired state will change in a negative way). Stress appraisals relate to harm/loss, threat, and challenge. In harm/loss, some damage to the person has already happened, for example a serious illness. Threat refers to anticipated harms/losses; the adaptive significance of this kind of appraisal is that it allows for

anticipatory coping. Challenge appraisal focuses on the potential for gain or growth in an encounter, and is characterized by pleasurable emotions (e.g., eagerness, excitement). Challenge appraisals are more likely to occur when the person has a sense of control over the situation. In “challenge” the person is choosing to fight the odds. Although threat and challenge are separate constructs, they can occur at the same time, and the relationship between them can shift as the encounter progresses (Lazarus & Folkman, 1984). For example, a situation that is perceived as more threatening than challenging can later be appraised as more challenging than threatening because of coping processes that allow the person see the situation in a different light.

Primary appraisal is an evaluation of the relevance of the situation. It asks, “Am I in trouble?” Secondary appraisal asks, “What can I do?” Secondary appraisal is an evaluative process that judges what coping options are available, the likelihood that a selected coping option will work as intended, and the likelihood that the person can apply a strategy or strategies effectively. Secondary appraisals of coping options and primary appraisals of the situation interact to determine the degree of stress and the emotional reaction. The interplay between the two can be complex, and depends on the individual.

Reappraisal is an additional concept in this framework (Lazarus & Folkman, 1984). It is a changed appraisal of a situation based on new information from the environment, and/or from the person’s own reactions. This is a type of feedback, where the reappraisal follows an earlier appraisal in the same situation and modifies it. Reappraisal and appraisal are the same basic concept, differing only in the time at which they occur in the unfolding of a situation. Defensive reappraisal is any effort to reinterpret the past more positively, or to deal with current threats/harms by looking at them in a less damaging light (Lazarus & Folkman, 1984).

The concepts of appraisal and reappraisal lead to the concept of coping. Coping is a process and is defined as “constantly changing cognitive and behavioral efforts to manage specific

external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141). Coping as a process has three main features (Lazarus & Folkman, 1984). First, what the person actually does or thinks. Second, to evaluate coping we need to know what the person is coping with: what the person actually says or does needs to be put in a context. Third, coping is in a state of flux, a person may need to rely more heavily on one form of coping at one time than another. Coping is a dynamic process and is a function of the appraisals and reappraisals of the situation by the person involved. Changes in the coping efforts chosen by the person can be a result of coping efforts directed at environmental change, inward-directed coping that changes the personal meaning of the situation or changes understanding, and/or environmental changes that are out of the person’s control. Wherever the shift comes from in the person-environment relationship, the shift will lead to a cycle where the person re-evaluates the situation, its significance, and what action can be taken. Therefore, the coping process is continuously mediated by cognitive reappraisals.

There are two types of coping: problem-focused coping, directed at managing the problem, and emotion-focused coping, directed at regulating emotional responses to the problem (Lazarus & Folkman, 1984). Generally speaking, problem-focused coping is more likely when the situation is appraised as amenable to change, and emotion-focused coping is more likely when an appraisal is made that nothing can be done to modify the environment.

There are many different emotion-focused coping strategies. Cognitive appraisals form one subset of emotion-focused coping (Lazarus & Folkman, 1984). They are aimed at decreasing emotional distress and include such strategies as avoidance, minimization, distancing, selective attention, positive comparisons, and extracting positive value from negative situations.

“Cognitive reappraisals” are cognitive efforts that change the meaning of the situation without changing it objectively (Lazarus & Folkman, 1984). Cognitive appraisals do not need to be

conscious; emotion-focused coping (e.g., maintaining hope, denying facts and negative implications, refusing to acknowledge the worst in a situation) can sometimes fall into the realm of self-deception. Successful self-deception may occur without awareness.

Problem-focused coping strategies focus on resolving the problem and are used to define the problem, think of alternate answers, do a cost-benefit analysis of alternative courses of action, choose a course of action, and act. Problem-focused coping strategies also include strategies directed inward and intended to help the person manage the problem, such as lowering the level of ego involvement, changing the level of aspiration, and finding alternative channels of gratification (Lazarus & Folkman, 1984).

Emotion-focused coping and problem-focused coping can both facilitate and impede each other. For example, an individual who is recently diagnosed with an illness may collect and evaluates information. This may lead to uncertainty and thus increased anxiety. The person becomes trapped in a cycle of problem-focused coping, which increases emotional distress and interferes with emotion-focused coping mechanisms like avoidance, which could be used to reduce anxiety (Lazarus & Folkman, 1984).

In addition to coping strategies, coping resources also play a role in managing a distressing event. Resources are what the person has to draw on to facilitate coping (Lazarus & Folkman, 1984). There are a number of resources to consider when evaluating which coping strategies are mobilized (Lazarus & Folkman, 1984). For example, health and energy may facilitate effective coping. A person having a positive view of him/herself is also an important psychological resource for coping. Problem-solving skills (i.e., ability to search for information, analyze the situation, weight the costs and benefits), and social skills (ability to behave and communicate with others in a socially acceptable manner, increasing the likelihood of receiving social support) are also important. The presence of these skills and how they are used depend on the individual

who is faced with the distressing situation. Social support and material resources (e.g., money and the things money can buy to help reduce stress) are also a consideration.

Some things can limit a person's ability to mobilize coping. Personal constraints, or the internal values and beliefs that dictate certain actions or feelings, can be limiting. There are also environmental constraints, such as limited resources that affect the choices the person has in terms of coping strategies. Also, if the level of threat experienced by the person is too high, the appraised high threat will interfere with problem-focused coping due to its effects on cognitive functioning and information processing.

In summary, Lazarus and Folkman's (1984) theoretical framework of stress and coping is the current dominant psychosocial framework. Their theory takes into account changes over time, and flexible use of coping strategies depending on appraisals of the environment. Coping is a dynamic process, where the person-environment interaction is key. Thus, breast cancer treatment as a process presents the patient with different stressors to be coped with at each stage of treatment. In the present study, the process-nature of stress and coping was used to guide my interview questions. I asked the women to recall their most salient stressor and how they coped with that stressor at each stage of treatment. In order to investigate stress and coping over a time period that presented a variety of stressors, I defined "treatment" as both breast surgery and at least one adjuvant therapy.

### *Sources of Stress During Breast Cancer*

Breast cancer presents multiple stressors, for example, breast cancer may be appraised as a threat to life, an assault on femininity, or a disruption to family and work (Landmark & Wahl, 2002; Spiegel, 1990). All treatments for breast cancer (i.e., breast surgery, chemotherapy, radiation therapy, and hormone therapy) cause difficult physical side effects such as nausea, vomiting, fatigue, and pain (Canadian Cancer Society website, 2006; Wengstrom et al., 2001). In

addition to the effects of treatment, some women may feel apprehension and anxiety before a particular treatment stage begins (Saares & Suominen, 2005; Thomas-MacLean, 2004). The severity of what a woman with breast cancer faces in treatment is summed up in the phrase often used to describe a treatment course of surgery, radiation, and chemotherapy: “Slash/Burn/Poison” (Langellier & Sullivan, 1998; Thorne & Murray, 2000).

Breast surgery (lumpectomy or mastectomy) is increasingly performed on a short-stay basis (Saares & Suominen, 2005). Excluding the implications of breast cancer (e.g., disability, death), surgery itself (including anesthesia) is a significant threat. Women may find some of the procedures before the surgery unpleasant, and common post-operative effects include nausea, fatigue, and pain (Saares & Suominen, 2005). Some women may experience distress before their breast surgery. Montgomery et al. (2003) performed a quantitative study in order to find the sources of anticipatory distress among breast surgery patients. The authors recruited 61 women between the ages of 22 and 77 years who were scheduled for either an excisional breast biopsy or a lumpectomy. Before their surgery, the participants completed a questionnaire packet that measured distress, worry about cancer and surgery, trait anxiety, optimism, and pessimism. The results indicated that both personal and contextual factors contributed to patients’ distress prior to breast cancer surgery. The greatest pre-surgical distress was found in participants who were more worried about the breast lump itself, and the effects of the surgery, whereas less distress was found in participants who tended to be optimistic in their outlook. Distress was not related to diagnosis; that is, the type of prognosis did not predict distress levels, suggesting that other competing concerns may take precedence (Montgomery et al., 2003). The use of questionnaires limited this study, as they did not assess all possible factors that may influence distress. Perhaps they would have found additional influencing factors if they had used different measures, or used interviews to ask women what factors were causing their distress.



Cowley et al. (2000) investigated adjuvant chemotherapy, and described the process of repeated rounds of chemotherapy as “the rollercoaster effect.” These authors interviewed 13 women who were between the ages of 20 and 65, had completed 6 rounds of chemotherapy 6 months earlier, and had no signs of recurrence. They used the grounded theory approach of Strauss and Corbin (1990) to analyze the transcripts. “The rollercoaster effect” referred to the ups and downs that the women experienced during adjuvant chemotherapy. As a result of their chemotherapy, the women reported a range of side effects that included fatigue and illness. Just when they were beginning to feel better, they had to repeat the treatment cycle. The repeated cycles of illness and recovery had a cumulative effect on the women, and the women felt worse as chemotherapy progressed. For the women in this study, adjuvant chemotherapy presented increasingly difficult and distressing symptoms over the course of the treatment. The qualitative approach allowed the women to explain their experience with chemotherapy.

People who have not undergone breast cancer treatment may assume that once treatment has been completed that the stress of treatment is over. However, Thomas-MacLean (2004) found evidence to the contrary. Twelve women (age range 42 to 77) participated in 2 in-depth interviews each, for a total of 24 interviews. These women had undergone breast cancer treatment at least one year previously, and their treatment consisted of various combinations of mastectomy, radiation, chemotherapy, and hormone therapy. The questions the author used were generated from an analysis of the transcript of a 5-member focus group meeting that she had run before the interview process. The author stated that the transcripts of the interviews were analyzed following established phenomenological guidelines, however, details of the analysis were not provided. Thomas-MacLean wrote that it was clear from the data that for these women, breast cancer treatment involved suffering and pain. For example, some of the participants had a “port” installed in preparation for chemotherapy. The port is a catheter that is installed in the

space between the collarbone and the breast. Installing the port is a same-day procedure that is done without the use of a general anesthetic. Chemotherapy drugs can then be administered through the port, eliminating the need for multiple needle punctures. One participant described the process of having a port for her chemotherapy installed as “pretty stressful” and “distressing.” Another participant wondered if “maybe the cure was worse than the disease.” Considering the difficulty of their treatment, an understandable assumption would be that ending treatment would be a relief. However, some women in this study felt distressed when their treatment was completed. One woman stated she felt “lost,” whereas another woman said she felt “let down.” Thus, the findings from this study revealed that the end of treatment has the potential to be a stressor for some women. Questionnaires may not capture the feelings women have at the end of treatment. The use of interviews in Thomas-MacLean’s study allowed the women to share their experience with chemotherapy.

Perhaps the stress a woman with breast cancer experiences also depends on her developmental stage. Dunn and Steginga (2000) attempted to discover if young women (i.e., young with respect to the experience of breast cancer) had unique concerns about breast cancer. To participate, women had to meet two criteria: (a) feel that they were “young,” and (b) had experienced breast cancer. Twenty-three women with breast cancer (age range 31 to 47 years), who were between 1 month and 7 years post-treatment, completed the study. The authors used a mixed-methods design including focus groups, in-depth interviews, and a three-round iterative survey.

The interviews did not focus on breast cancer treatment, rather, they asked participants a series of questions that prompted participants to define “young” and talk about what concerns they thought were unique to “young women with breast cancer.” According to these women, three criteria defined “young:” (a) children not yet in secondary school, (b) pre-menopausal, and

(c) of child-bearing age. The concerns identified were: (a) fear of not living to see their children reach adulthood, (b) fear of infertility, (c) fear of not being able to have children due to a recurrence of the cancer, and (c) a general feeling of concern that they were too young to get breast cancer. The women also expressed feelings of anxiety, depression, fear, and anger.

Despite the fact that the focus was not only on treatment for breast cancer, this study suggests that it may be beneficial to investigate the stressors of young women with breast cancer apart from older women. However, Dunn and Steginga (2000) focused exclusively on the criteria “young,” and specifically asked this group of women what concerns are unique to “young” women. It is not clear that they would have achieved the same results if they had asked this same group of women to identify their concerns without specifying that they be concerns unique to young women. It is also possible that a different group of women, who may not define themselves as “young” could raise the same concerns.

In summary, each stage of breast cancer treatment presents its own stressors. Breast cancer treatment progresses and changes over time, therefore, the stressors that women with breast cancer experience also change over time. Dunn and Steginga (2000) indicated that “young” women find unique issues stressful, suggesting that when looking for sources of stress, it might be useful to restrict the age range of participants in order to get a homogenous sample. However, in the present study, I did not limit the age range of the participants for two reasons: (a) I wanted to increase the chances of recruiting a sufficient number of participants, and (b) I asked women to recall their most salient stressor at each stage of treatment, and did not use age to guide the questions as done by Dunn and Steginga. There may not be differences in the recalled salient stressors based on age if the questions do not focus on age as a criterion. In the present study, the use of interviews allowed the women to recall and to explain in-depth, their most salient stressor at each stage of treatment.

*Coping with Breast Cancer*

Cancer presents a variety of threats with which women must cope – painful or distressing symptoms, ambiguity about the prognosis, and changes in social relationships (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992; Lazarus, 1993; Wengstrom et al., 2001). Early research on coping with breast cancer dealt with a disease that typically had a poor prognosis and was treated with aggressive surgery and adjuvant therapy that had debilitating side effects, and as such, often addressed coping with death (Compas & Luecken, 2002; Jacoby, 2003). As a result, the picture of adjustment to breast cancer was characterized by significant distress and trauma (Compas & Luecken, 2002). Advances in medicine have reduced the side effects women must endure, and increased the survival rates (Compas & Luecken, 2002; Jacoby, 2003). In the past decade, the percentage of Canadian women who survive breast cancer has increased by 30% (B.C. Cancer Agency website, 2006). Despite these advances, treatment of breast cancer continues to present women with a number of stressors that they must deal with (Canadian Cancer Society website, 2006; Wengstrom et al., 2001).

On the surface, the literature on coping with breast cancer seems contradictory. Some studies have found that women who used denial and avoidance as coping strategies reported less distress (Meyerowitz, 1983; Watson, Greer, Blake, & Shrapnell, 1984), whereas others found that confrontive approaches were better in handling breast cancer (Carver et al., 1993; Shapiro et al., 1997). However, Suls and Fletcher (1985) performed a meta-analysis of 43 studies of coping with cancer and found that avoidance strategies were effective when outcome measures were immediate, while attention strategies were more effective when outcome measures were long term. Similarly, Heim et al. (1997) found that denial kept distress low over the course of the disease, while diverting strategies became relevant during rehabilitation. The research studies

that have delved further into coping strategies have found that coping with breast cancer is dependent on the stage of the disease and the process of treatment.

Heim et al. (1997) used semi-structured interviews to investigate the coping strategies and psychosocial adaptation of 74 women (aged 35 to 88 years) with breast cancer over a period of 3 to 5 years. Participants all had a mastectomy, 38% received chemotherapy, and 10% had radiation therapy. Several interviewers were involved over the course of the study, and all received "extensive training" in assessing videotaped interviews in order to achieve satisfactory inter-rater reliability. Interviewers completed the Bernese Coping Modes Scale, Social Adaptation Scale, and the Emotional State Scale. For the analysis, the authors divided the breast cancer experience into eight distinct clinical stages of illness: detection/diagnosis, hospitalization/surgery, post-discharge/convalescence, post-discharge/adjuvant therapy, rehabilitation/no new symptoms, metastatic disease/recurrence, terminal illness, and dying.

Heim et al. (1997) found that five coping strategies were used: (a) support, (b) self-control (problem-analysis, self-validation, and giving meaning), (c) diverting from illness, (d) denial, and (e) negative-emotional (resignation, rumination, rebelling, anger, self-accusation, and withdrawal). The data indicated that there was a preference in the way the strategies were used. Support was always the coping strategy of choice, self-control was second, diverting from illness was somewhere in the middle, and denial and negative-emotional were the least preferred by the participants. Overall, women who expressed high psychosocial adaptation tended to cope in an active, constructive, task-related manner. Women who showed poor adaptation tended to cope using rumination, resignation, rebelling, self-accusation, and release of anger, as well as tending to deny the illness on the whole.

Heim et al.'s (1997) study identified a number of coping strategies, however, they did not provide illustrative examples of each coping strategy. The few words that were used to describe

each coping strategy were insufficient to ensure that readers have the same understanding of what each coping strategy entails. In addition, because multiple interviewers completed the questionnaires for the participants, there is a chance that, despite the authors' assurances of inter-rater reliability, different interviewers made different decisions about how to complete the questionnaires. This study also did not provide any indication of the stressors with which the women were coping. Rather than use quantitative questionnaires that narrowly conceptualize the coping strategies women use, the use of interviews in the present study allowed the participants to contextualize their coping strategies.

Ray et al. (1982) examined coping strategies during breast cancer by re-examining interviews of breast cancer patients that they conducted in an earlier study about lay and medical perceptions of breast cancer. They chose to analyze interviews from 28 women who had a mastectomy as treatment for early stage breast cancer. The authors did not give any additional information about these women, such as demographic information, or whether the women had additional treatment for breast cancer. The authors also did not explain the method they used to identify their coping themes. Despite the lack of information about the participants and the method, and the fact that their interviews did not focus on breast cancer treatment, it is useful to be aware of the coping themes they found. Ray et al. identified six coping themes used by women when experiencing breast cancer: rejection, control, resignation, dependency, avoidance and minimization. In "rejection," the woman sees herself as the victim of an unfair situation, and may rebel against the violation she feels. This rebellion may be displaced in the form of suspicion or hostility towards the people who are involved in the breast cancer treatment. In "control," the woman sees herself as facing a challenge, and has a sense of personal agency. She tries to gain mastery over or adapt to the problem of breast cancer. "Control" may also emerge as a desire to collect information in order to be able to predict events. In "resignation," the woman

feels powerless and sees events largely determined by an external force. Resignation has two poles: (a) an attitude of despair and giving up, and (b) an acceptance of what is inevitable. In "dependency," the woman sees events as out of her control, and may depend completely on external resources. In "avoidance," the woman perceives herself as under threat, and avoids situations or thoughts that will cause anxiety. She may avoid sexual contact, looking at herself, or information relevant to illness or death. She admits the unpleasantness but withdraws attention from it. In "minimization," the woman sees herself as secure and not threatened. She may dismiss any possibility of danger, or argue that the idea of danger does not apply in her case. The authors state that the type of coping used depends on the woman, the type of stressors, and the context. This article's major weakness is the lack of information about participants and method. However, these themes do contribute to the literature on coping with breast cancer, and emphasize the importance of the person-environment fit.

Osowiecki and Compas (1999) conducted a prospective study that examined perceptions of control, coping efforts, and emotional distress in women newly diagnosed with breast cancer. Seventy women (age range 36 to 80 years) were assessed near diagnosis and at 3- and 6-month follow-ups. The authors used structured interviews to collect information on perceptions of control. Participants were asked to rate how much control they felt they had on a scale of 1 (*not at all*) to 4 (*a great deal*). Symptoms of emotional distress and coping strategies were assessed using standardized questionnaires. The results indicated that high perceived control and problem-focused engagement coping (problem solving and cognitive restructuring) were associated with lower symptoms of distress near the time of diagnosis only. Emotion-focused disengagement coping (social withdrawal and self-criticism) was related to higher symptoms of distress. The use of problem-focused disengagement coping (avoidance and wishful thinking) predicted increased symptoms of distress from the 3-month to the 6-month follow-up. This study indicated that

active problem-solving coping is related to lower levels of distress. However, the study's use of questionnaires limited the types of coping strategies that the authors were able to investigate. In addition, the authors did not describe the coping strategies as they related to the specific stressors. More in-depth descriptions of the coping strategies would have been useful. An open-ended interview may reflect a greater variability in the coping strategies used by women experiencing breast cancer, as well as illuminate relations among the context, coping strategies, and stressors.

Wengstrom et al. (2001) interviewed 134 participants to investigate coping strategies during radiation therapy. Participants were interviewed before radiation started, at the end of radiation, and 3 months after radiation. Participants were 37 to 83 years old and their backgrounds (education, employment, marital status) were varied. All had already undergone either a lumpectomy or a mastectomy, and some participants had also undergone chemotherapy or hormone therapy. The authors performed a content analysis on the data with the help of a computer program. Five major themes ran through the three measuring points: (a) daily activities – activities relating to home and work, (b) treatment – statements concerning treatment, (c) health – statements concerning physical symptoms, (d) psychological situation – statements concerning emotions and reactions, and (e) self-care – activities done to make self feel better.

Before radiation treatment began, the major theme was the women's daily activities. The women spoke of trying to live life as usual – caring for their families, doing housework, and social activities with friends. Their coping at this time involved doing things that gave a sense of normalcy. Also, social interaction distracted them from their treatment. Activities that the women did for themselves, such as reading, going for walks, and resting, were also common before treatment. At the end of radiation treatment, work and home activities played a more minor part, and women were coping by doing activities that made them feel better. Social



activities with family and friends were also more important than they were before radiation began, suggesting that social support was helping the women to cope with their treatment. At the end of radiation treatment, the physical effects of treatment were taking their toll, and the women spoke more about the physical symptoms. Three months after radiation ended, work activities related to family and home were once again important. These results demonstrate that, for these women, coping with radiation therapy changed over time. Coping strategies that were important before radiation began were less important by the end of radiation therapy. The use of a qualitative approach allowed the women to express what they found important, and captured the process-nature of coping with radiation therapy.

In summary, coping strategies used during breast cancer change with the changing stressors and changing context. The research reviewed indicates that the coping strategies, and the usefulness of the strategies, vary with the stage of breast cancer. One drawback to many studies is that they did not fully describe the coping strategies that they found. In addition, the stressors, or what the women were coping with, were also rarely mentioned in any detail. In the present study, I focused on the entire course of breast cancer treatment, a time that is not often focused on in the literature. I used in-depth interviews to give the women the freedom to describe their coping strategies and stressors in their own words. In order to determine the coping strategies used, I asked the participants to first recall their most salient stressor at each stage of breast cancer treatment (the context for the coping strategies), and then how they coped with that stressor.

#### *Current Literature: Stress, Coping, and Breast Cancer*

Hilton (1988) identified “uncertainty” as a stressor, and investigated both the concept of “uncertainty” and the strategies that women used to cope with it. The idea that “uncertainty” is a stressor is supported by literature that demonstrates that women with breast cancer experience

uncertainty about the possible spreading of the cancer, and uncertainty about suffering and death (Landmark & Wahl, 2002; Pierce, 1993; Wonghongkul, Moore, Musil, Schneider, & Deimling, 2000). Hilton used a phenomenological approach to interview 16 women previously diagnosed with breast cancer. The women varied in age from 34 to 75 years, and the average length of time since diagnosis was 4 years. Breast cancer treatment for the women was varied and included mastectomy, lumpectomy, radiation, chemotherapy, and a combination of radiation and chemotherapy. Two women had had recurrence of breast cancer. In this retrospective study, Hilton conducted a phenomenological analysis of the transcripts to identify common themes.

Uncertainty was defined by the participants as “a perception that ranges from a feeling just less than surety (certainty) to a feeling of vagueness” (Hilton, 1988, p. 220). Major themes that emerged from the interviews were: (a) not being able to tell the future, (b) not feeling secure and safe, and (c) being in doubt. Some women expressed feeling doubt when given treatment options, and later, feeling doubt that they had chosen the correct one. A number of personal beliefs about cancer that influenced feelings of uncertainty also emerged; cancer means death, suffering, and destruction. Women experienced cancer as invasive, and had feelings of being tainted. The feelings that were generated by this underlying sense of uncertainty included anxiety, wonder, fear, frustration, depression, curiosity, and helplessness. Anxiety and worry were the most predominant anxiety-emotions. Women who expressed more feelings of certainty had more positive emotions associated with that feeling, including relief, relaxation, hope, and confidence.

The strategies employed to cope with uncertainty were varied, and some women did not use any coping strategies. The nature, degree, and timing of the uncertainty influenced the coping strategy used. Women diagnosed with cancer have to deal with the disease itself and the process continues beyond treatment because of chances of recurrence and other uncertainties. The coping

themes Hilton (1998) identified were: (a) mobilizing resources, (b) focusing on the positive, (c) buffering the situation, (d) modifying the situation, and (e) minimizing stress effects.

“Mobilizing resources” were information-seeking behaviors and behaviors where the woman looked for support from others. “Buffering the situation” were behaviors that controlled the meaning of the problem, such as minimizing, avoiding, and denying. These behaviors were used at various times throughout the illness; initially it was difficult for the women to minimize their illness, but this changed later on for some of the women. Women spoke of not thinking about the cancer, trying to forget about it, or trying to not worry about it. Many women spoke of focusing exclusively on the present, and not looking into the future. “Modifying the situation” included behaviors that would decrease the chance of recurrence, increase the chances of early detection, and allow the women to handle problems as they arose. Finally, “minimizing stress effects” were behaviors aimed at helping the women accommodate existing stress rather than being overwhelmed by it, for example, using stress reducers such as self-hypnosis. Hilton stated that each woman’s appraisal and coping response to her breast cancer was unique and fluctuated over time.

Different coping strategies had different outcomes. Information seeking usually resulted in less uncertainty, although at times it raised further questions. Information helped some women get control over their situations. The use of modifying coping strategies also helped some women gain a sense of control. The use of buffering strategies helped most women regain a sense of normalcy. For example, focusing on the present helped some women deal with uncertainty by giving them a defined period to deal with, rather than a vague and uncertain future. Use of strategies to minimize stress did not decrease uncertainty, and occasionally increased anxiety. Hilton’s (1998) research findings indicated that a variety of coping strategies were used to deal with the stress of uncertainty, and that different coping strategies were useful at different times

during the disease. The strength of this study is that it used open-ended interviews to allow women to express what “uncertainty” meant to them and how they coped with it. The stressor “uncertainty” and the coping strategies were all described in detail.

Pamela C. Fischer (2001) wrote a personal view of the breast cancer experience. She outlined her stressors and the coping mechanisms that she used during her experience of breast cancer. Dr. Fischer was diagnosed with breast cancer at 47 and wrote that she recalls feeling shocked, numb, and in a state of disbelief. She wondered how she could feel fine and yet have a life-threatening disease. She realized that her identity as a healthy woman had changed to that of a patient facing a life-threatening disease. Dr. Fischer comments that it was during the emotional upheaval following the diagnosis that she was asked to make decisions regarding her course of treatment, and that she handled this situation by gathering information. Dr. Fischer chose “conservative” treatment, and went through a biopsy, then a lumpectomy, then a bilateral mastectomy, and reconstruction. Between surgeries, she continued to work at her psychology practice and found that working helped divert her attention from her illness. Dr. Fischer admitted to anxiety that occasionally became overwhelming, and her coping strategies in these cases were cognitive, challenging her negative thinking. She also commented that social support was key during her breast cancer experience. She indicated that, in essence, breast cancer is a “painful and lonely journey” (Fischer, 2001, p. 106), and that she found hope a necessary coping tool. This personal story contributes useful information about one woman’s experience with breast cancer, and could be added to by interviewing women with diverse backgrounds (e.g., ethnic, social class) about their experience with breast cancer.

In summary, there is very little research that investigates the stressors that women face during breast cancer, and the strategies they use to cope with those stressors. A fuller understanding of stress and coping during breast cancer requires knowledge of both the stressors

and the strategies used to cope with those stressors. This knowledge can be best accessed through interviews that allow women to freely express what was a stressor and how they coped with that stressor. The present study addressed the gaps in the literature by investigating stress and coping during the entirety of breast cancer treatment, a time frame that has not often been investigated.

### *Summary of the Breast Cancer Stress and Coping Literature*

There is a paucity of research in the stress and coping literature focused on the treatment aspects of breast cancer. Treatment is an important part of a woman's experience with breast cancer, therefore, I reviewed literature that examined both stress and coping with breast cancer, and stress and coping during breast cancer treatment. Very little research has placed the coping strategies into the context of the stressors, so for the purpose of this summary, I present the stressors and coping strategies from the breast cancer literature separately.

Breast cancer may be appraised as a threat to life, and stands out from other life-threatening diseases due to the social discourse – breast cancer is intrinsically linked with femininity and sexuality, and the discourse often focuses on issues such as body image, identity, and self-worth (Landmark & Wahl, 2002; Thorne & Murray, 2000). Therefore, breast cancer treatment that threatens the breast may also threaten the woman undergoing treatment. In addition to the possible threat to life, and the possible threat to femininity and sexuality, studies have identified other stressors. Some women going into a treatment stage may feel anticipatory distressing emotions, such as uncertainty, anxiety, and distress (Hilton, 1998; Montgomery et al., 2003; Saares & Suominen, 2005; Thomas-MacLean, 2004). Once treatment begins, women face a host of physical effects they must deal with that depend on the stage of treatment they are receiving. Women have reported a variety of distressing physical symptoms, such as pain, nausea, vomiting, and fatigue (Cowley et al., 2000; Fischer, 2001; Saares & Suominen, 2005; Thomas-

MacLean, 2004; Wengstrom et al., 2001). Throughout treatment, women must also deal with their emotional reactions, and have reported distressing emotions such as uncertainty, anxiety, fear, worry, frustration, and helplessness (Dunn & Steginga, 2000; Hilton, 1998; Spiegel, 1990). Thomas-MacLean (2004) found that the end of treatment might also be distressing for some women. There is agreement in the literature that breast cancer presents both physical and emotional stressors, and that these stressors change over time due to the nature of the disease.

A plethora of coping strategies have been identified in the breast cancer literature. Oftentimes, authors choose their own names for the strategies they identify, and this has resulted in a pool of research that seems disjointed. In addition, many quantitative studies did not provide explanations of their coping strategies, and the few words used to describe their coping strategies (sometimes only a title) were not always sufficient to ensure the readers' understanding of what each coping strategy entails. However, a close inspection of the literature revealed several commonalities.

Some researchers have found avoidance strategies during breast cancer, where the women avoid situations or thoughts that may cause them anxiety. For example, women may avoid information relevant to their illness, they may avoid looking at themselves, or they may avoid social situations (Heim et al., 1997; Osowiecki & Compas, 1999; Ray et al., 1982). Research has found that some women use minimization and denial, where they minimize or deny the idea of danger (Hilton, 1998; Ray et al., 1982). Diverting strategies have also been found, where women do things to divert their attention from the experience of breast cancer (Heim et al., 1997; Wengstrom et al., 2001). Several authors have found action-oriented strategies during breast cancer, such as collecting information, problem analysis, problem solving, challenging negative thinking, seeking social support, and doing activities for the self (Fischer, 2001; Heim et al., 1997; Hilton, 1998; Osowiecki & Compas, 1999; Ray et al., 1982; Wengstrom et al., 2001). Ray

et al. (1982) identified three coping strategies that were not replicated in any of the other reviewed research: (a) dependency – depending on external resources, (b) resignation – despairingly giving up and accepting the inevitable, and (c) rejection – feeling like a victim of an unfair situation and rebelling against the perceived violation.

There are a vast number of seemingly unconnected coping strategies identified in the literature, however, a close look at the definitions of the coping strategies demonstrates that there is overlap amongst different studies. In addition, there is agreement regarding the stressors that breast cancer presents to women. What is missing is research that: (a) focuses on the entire span of treatment, and (b) places the coping strategies in the context of their stressors. The present research addressed the gap in the literature by asking the question: “At each stage of breast cancer treatment, what was the most salient stressor, and how did the women cope with that stressor?”

### *Study Rationale*

Breast cancer is the most frequently diagnosed cancer in Canadian women (Canadian Cancer website, 2006) and breast cancer treatment is a process that presents a variety of stressors over time. Although there is research that addressed the stress of breast cancer, or the coping strategies used during breast cancer, there is minimal research that: (a) focused on the treatment for breast cancer, and (b) linked the stressors that women face with the coping strategies they use. There is agreement in the literature that breast cancer treatment is a process, however, most research that has examined treatment has focused on only one stage of treatment at a time. There has been a paucity of research that investigated the entire process of breast cancer treatment, and examined the different stressors presented over time, and the coping strategies that are mobilized at different times.

Because of a personal interest in stress and coping during treatment for breast cancer, and a gap in the literature, I investigated the process of stress and coping during breast cancer treatment (surgery and adjuvant therapy) by asking women to recall their most salient stressor at each stage of treatment, and how they coped with those stressors. Treatment presents a host of issues for women to cope with, and it may be difficult for women experiencing treatment to choose their most salient stressor, therefore, I chose a recall study design. Participants were at least one year post-treatment, which allowed sufficient time post-treatment for women to identify the most salient stressor at each treatment stage. The question that guided this research was: "At each stage of breast cancer treatment, what was the most salient stressor, and how did the women cope with that stressor?"



## CHAPTER THREE

### METHOD

In this study, I asked 10 women to recall their most salient stressor at each stage of breast cancer treatment, and how they coped with that stressor. Treatment was defined as at least one breast surgery and at least one form of adjuvant therapy. The question that guided the research was: "At each stage of breast cancer treatment, what was the most salient stressor and how did the women cope with that stressor?" I used constant comparative analysis to access commonalities (i.e., common themes or patterns of experience) in the women's treatment experiences.

#### *Participants*

Study participants were 10 women ranging in age from 47 to 74 years old. All participants were Caucasian, fluent in English, and lived in the Greater Vancouver area. Eight participants were married, and two were single. Six of the participants had at least one child. The education levels of the participants ranged from high school graduate to a doctorate degree; the majority of the participants held at least one university degree. Six participants were employed outside the home, two were retired, and two were homemakers (see Appendix A).

The inclusion criteria for this study were: (a) treatment for breast cancer consisted of at least one breast surgery and at least one type of adjuvant treatment, (b) no evidence of recurrence at a minimum of one year post-treatment, and (c) no concurrent medical or mental illness. The first criterion ensured that all the women experienced a treatment protocol that presented a variety of issues over time, facilitating the exploration of breast cancer treatment as a process. This study investigated the first-time diagnosis, so women who experienced recurrences were excluded in order to eliminate any possible effect that this could have on the recall of their first treatment experience. One year post-treatment was selected as a reasonable amount of time to allow

reflection on what was most stressful during treatment. Initially, I attempted to recruit participants at least one year after they had completed all stages of breast cancer treatment, however, I had difficulty finding a sufficient number of interested women. Several women who contacted me in response to advertisements informed me that to their knowledge most women were prescribed tamoxifen (i.e., a hormone therapy taken daily in a pill form) as a final stage of treatment, and that the recommended time to be on tamoxifen was 5 years. I was concerned that the criterion of being one year post-treatment would result in an insufficient number of participants. Therefore, I broadened the criteria and included women who were currently taking tamoxifen as long as the other types of treatment had concluded at least one year ago. Because concurrent physical or mental illnesses could also interfere with exploration of the breast cancer treatment experience, women who had either were not included.

Nine participants had completed all treatment stages at least one year prior to their interview. One participant was taking tamoxifen when interviewed, however, surgery and other adjuvant treatment had been completed four years prior. This woman agreed to participate with the knowledge that I would not be asking her about her experiences with tamoxifen. The participant indicated that she was in her fourth year of taking tamoxifen, and she did not feel that her recollection of other treatments would be affected.

### *Participant Recruitment*

Participants were recruited from Greater Vancouver through four methods: (a) an advertisement placed in the quarterly newsletter “Abreast in the West,” (b) an email advertisement distributed to the “Abreast in a Boat” Dragon Boat teams, (c) a notice posted on the Canadian Breast Cancer Network Clinical trials and Research Studies website, and (d) by word of mouth. The advertisements invited interested women to contact me by either email or telephone (see Appendices B and C).

During the initial telephone contact (see Appendix D), I explained the purpose of the study (to uncover through semi-structured interviews, the stressors encountered during breast cancer treatment, and the ways of coping with those stressors) and reviewed the criteria for participation. Ten women met the inclusion criteria and were interested in participating.

I informed the participants during the initial conversation that they needed to read and sign a consent form before the interview. All ten participants wanted to wait until the interview to read the consent form. We scheduled the interview for a time and place convenient and comfortable for each participant (e.g., their home, or an office).

Before the interview began, each participant read and signed the consent form (see Appendix E). None of the participants had questions at that time, and all were given a copy of the consent form for their records.

### *Interview Process*

After the consent form was signed, I gave the participants a copy of the questions I was using as an outline for the interview (see Appendix F). Once the participants had read the outline and indicated that they were ready to begin, I read aloud an opening statement: “The questions I will ask are designed to guide us through the process of your breast cancer treatment. One of the things I will ask is what you found most stressful about certain aspects of your treatment. By ‘stressful’ I mean things that you found demanding, difficult, disturbing, or distressing. I will also ask what you found most stressful about adjuvant therapy. By adjuvant therapy, I mean radiation, chemotherapy, and hormone therapy, such as tamoxifen and arimidex. I’d like to focus on the treatment for breast cancer – if there was a major stressor that happened that was not related to your treatment, you will have an opportunity to describe that at the end, when you fill out a demographic questionnaire.”

This statement ensured that the participants understood how I was defining “stress,” because, as noted in the Literature Review, there are different definitions for “stress” both in the academic

literature and in everyday language. In addition to the variety of definitions for “stress,” I assumed that the participants would not be familiar with the academic definition of “coping.” Therefore, following the women’s explanations of their most salient stressors, I asked the women how they “dealt with that stress.” If they spoke about a particular coping strategy, I then followed-up by asking what their intent was in choosing “that method to cope.” These measures ensured that my definitions were clear and that I was consistent across interviews.

After I had read the opening statement, I answered any remaining questions, and when participants indicated they were ready for the interview, I turned on the digital recorder and began the interview. I maintained an open and relaxed physical posture throughout the interview, and kept the interview progressing through the use of open questions, and non-verbal communication (e.g., nodding head, eye contact).

The interviews lasted from 45 to 75 minutes, and upon completion of the interview I turned the digital recorder off and conversed with the participants for a few minutes. Often the participants were interested in why I had chosen to study breast cancer, and were curious about what I hoped to do after I finished my thesis. During this conversation I had participants complete the demographic questionnaire (see Appendix G). This conversation helped me to bring the interview to a close and assess the comfort level of the participant. I had prepared a list of resources in case discussing their treatment triggered distress, but none of the participants appeared upset (e.g. flushed, in tears). Each participant expressed her interest in receiving a copy of the themes, and gave me her preferred method of contact (i.e., mail or email). I informed the participants that I would make a copy of their transcript available, if they were interested. None of the participants wanted a copy of their transcript.

The interviews were transcribed verbatim, with no alteration of grammar. The transcripts were then open-coded, and analyzed for common themes.

### *Data Security*

The transcripts were kept in a locked filing cabinet along with the digital audio files (burned onto a CD), demographic and contact information, signed consent forms, and a spiral notebook that contained all my notes and memos. Any information about places (e.g., hospital names) and third parties was deleted from the transcription.

### *Data Analysis*

Qualitative methods can give intricate details of phenomena that are difficult to convey with quantitative methods (Strauss & Corbin, 1990). As a research method, constant comparative analysis, a central feature of grounded theory, best addressed the research question. Therefore, I used constant comparative analysis to achieve conceptual ordering of the concepts. The data from the personal interviews were organized into discrete themes and then each theme was given a descriptive name (Strauss & Corbin, 1990). Data analysis included open coding, constant comparative analysis, and memo writing.

Open coding is a way of breaking down text into categories where the text is examined, compared, conceptualized, and categorized (Charmaz, 2000; Strauss & Corbin, 1998). I did a line-by-line analysis to generate my categories. This method allowed for the most detailed and the most generative analysis (Strauss & Corbin, 1990). Coding the text line-by-line kept me focused on what the participants were describing, instead of my own pre-conceptions. I grouped the codes into concepts, and give each concept a name. This conceptual label represented the phenomenon and was grounded in the text (Strauss & Corbin, 1990). The concepts were then grouped into seven themes – groups of concepts that pertained to the same phenomenon (Strauss & Corbin 1990).

### *Theoretical Sensitivity*

Strauss and Corbin (1990) discussed theoretical sensitivity – the ability to see what is there with analytic depth, in other words, to recognize what is important, and give meaning to the data. Theoretical sensitivity comes from familiarity with literature, professional experience, and personal experience. In my case, I have reviewed, and am familiar with, the literature. I have lived through my mother's breast cancer treatment, and thus have witnessed one woman's experience of breast cancer treatment. Over the years, we have discussed her experience, and I possess the insights that she has given me into her treatment. In addition, I have survived my own spinal fusion surgery, which has some parallels to the experiences reported by the participants in this study. The process of working with the data also increased my theoretical sensitivity.

### *Memos*

Memo writing is a way of recording data and the process of analysis (Strauss & Corbin, 1990). Memos can take several forms: code notes, theoretical notes, operational notes, and variations of these (Strauss & Corbin, 1990). Memos evolve throughout the research, and later memos may amend, support, extend, and clarify earlier ones. Memos help researchers gain analytical distance from materials – they assist in movement away from the data to abstract thinking, and then returning to the data to ground the abstractions into reality. I used memo writing throughout the research process. I kept a notebook in which I recorded all my thoughts, questions to myself, and insights. Diagrams are useful as the graphic representation of the relationships in the data (Strauss & Corbin, 1990); thus, I also recorded my attempts to diagram a relationship amongst the seven themes. In addition, I recorded all the notes that I took in my meetings with my advisor, Dr. Bonita Long, in this notebook.

As I worked with the data, I recorded questions and insights that I had in the notebook, and referred to those notes (i.e., memos) throughout the analysis process. My use of language in the discussion of the themes illustrates how the memos were used in the data analysis. During a meeting, my advisor asked if I was saying a particular event was “distressing” or a “stressor.” I wrote her question in my notebook, and added a notation “How am I using language?” I went back to the original transcripts and re-examined what the women had said during their interviews. In the notebook, under my advisor’s question, I wrote some examples of the women’s statements, and my thoughts about how I was representing their statements. Through this process, I was able to make an informed decision about how to use language when discussing the themes.

### *Personal Bias*

While working with the data, I remained aware of the effect my personal bias could have on the outcome. I chose the names of categories, and decided which pieces of the data were important. My bias with breast cancer treatment stems from family experience; I believe that treatment is a negative experience that presents a number of distressing or disturbing incidents that have to be dealt with in order to recover. I further believe that women who experience these stressors are resourceful and find ways to manage, or cope, with the stressors presented by treatment. During my research, I remained aware of my bias that breast cancer treatment is a negative experience that requires effort and strategies to recover. During the interview process, some of the participants indicated that there were times during treatment when they did not feel distress. For example, Lynn stated that she felt positive in the time preceding her first lumpectomy. Although my bias leads me to expect that people have negative feelings before surgery, I explored her positive feelings in more detail with her. Throughout the 10 interviews

and the data analysis, I made a determined effort to put my biases aside, and be open to all experiences.

### *Criteria for Evaluation of Research*

As suggested by Strauss and Corbin (1998), who stated that it is important to make explicit the criteria used to judge the merit of qualitative work, I present criteria that can be used to evaluate my thematic analysis.

Strauss and Corbin (1998) present three criteria for evaluating the adequacy of the research process: (a) how, and on what grounds, was the original sample selected; (b) what major categories emerged; and (c) what were some of the events/incidents/actions (indicators) that pointed to some of the major categories? Because I analyzed the data (interviews) for themes (concepts) an additional evaluative question was – does the data generate concepts, and what are their sources? I used these questions to confirm that the themes were grounded in the data. In addition to these questions, a process of verification was built into the study to ensure trustworthiness and dependability. Specifically, data collection and analysis occurred concurrently. In this manner, concepts emerging from the data were confirmed with new data, and new ideas were confirmed against previously considered data (Morse, Barrett, Mayan, Olson, & Spiers, 2002). My research supervisor reviewed both the interview transcripts and my coding process.

In addition to the above measures, each participant received a copy of her own interview summary and a copy of the findings, and had an opportunity to provide feedback on both (see Appendices H and I). Providing the participants with a summary of their interview and inviting feedback was my attempt to ensure that I accurately understood what each participant had told me about their experience with treatment. Four participants contacted me, and each stated she was pleased with her summary. One participant wrote: “I found it quite moving to read such a



sensitive description of my experience. It is well written and definitely accurate,” and another stated that the summary was a “very complete description of [her] situation.” I also invited feedback on the themes in order to ascertain if the findings fit or did not fit with the women’s experiences during treatment. Two participants offered feedback on the present study’s findings. One participant stated that the findings were “very, very interesting” and said that she was pleased to see herself represented in the quotations. The second participant stated that she could relate to the findings, and that she felt her experience with breast cancer treatment was represented. The second participant also felt that the findings elucidate how important it is for medical professionals to demonstrate more empathy and truthfulness when working with women with breast cancer. She hoped that these findings would be shared with agencies involved in breast cancer treatment. The feedback I received provides some evidence that I accurately represented these women’s experiences with breast cancer treatment, as they were told to me in the interview process.

## CHAPTER FOUR

### FINDINGS

The question that guided the interviews was: "At each stage of breast cancer treatment, what was the most salient stressor, and how did the women cope with that stressor?" Constant comparative analysis of the interview transcripts revealed seven themes and several sub-themes.

The themes were:

- (a) dimensions of time,
- (b) physical effects of treatment,
- (c) being prepared,
- (d) emotionality during treatment,
- (e) support from others,
- (f) thoughts to self, and
- (g) doing for self.

For these women, treatment for breast cancer was a process that was constantly changing, and as such, linear relationships are not apparent among the seven themes. Quotations are provided to help illustrate the themes, and each participant chose a pseudonym to ensure confidentiality. In addition, identifying information (e.g., place names) was removed from quotations. To help the quotations read more fluidly, words such as "um," "like," and "you know" were removed, as long as their removal did not affect the intent of the statement. If required, quotations were edited for clarity. The transcript line number follows the participant's name when quotations are used (e.g., Lynn (46) said...).

#### *Stress and Coping*

In the descriptions of the themes in this chapter, I was careful not to impose Lazarus's theoretical language on the women. In the findings, I describe the particular events as the women

described them to me – sometimes the women stated outright that an experience was “stressful” and other times they spoke about an experience as being “distressing.” Some women used the word “coped” and others did not. I kept the women’s own language in order to accurately reflect their experience. When over-viewing and summarizing the themes, I chose language that encompassed the women’s language. The word “distress” encompassed both what the women stated was “stressful” and what they described as “distressing.” The word “helpful” encompassed the things that the women stated helped them, and the specific coping strategies the women used.

### *Insights and Surprises*

Before exploring the uncovered themes, I outline some insights and surprises that arose as I worked with the transcripts. The women who participated in this study underwent a variety of different treatments for breast cancer. Of the 10 participants, there were eight different treatment combinations. In addition to the treatment combinations, the participants had diversified backgrounds and were at different life stages (see Appendix A). For example, some participants were married, and others were single. Some participants worked outside the home, others were homemakers, and others still were retired. Some participants had children, and others did not.

During the interviewing and transcribing process, I realized that some women spoke openly and at length about their stressors during breast cancer treatment, others less so. One participant, Lisa, stands out, because before the interview she told me how different she would be from everyone else. Lisa stated that she had maintained a very positive attitude during her breast cancer treatment, and that she worked hard to get healthy. Lisa felt that I would find that other women were more adversely affected by treatment than she was. I began my analysis with what I thought was the richest interview, then moved on to the next most rich interview, and so on, and left Lisa’s transcript to the last. The “richest” interview was the one in which the participant spoke the most freely, gave the most details about her experience, and responded in-depth to my

questions. The heterogeneity of the participants concerned me; I wondered if the participants were so diverse that I would not find common themes

However, as I worked through the interviews, I found that each woman had a unique response to treatment. Different treatments affected different women in different ways. Pain, for example, was often particularly distressing after surgery. Having been through surgery myself, I expected that. But, pain could also be distressing during tamoxifen treatment – as estrogen was removed from the participants' bodies joint-pain became distressing. One participant reported distressing pain during her radiation sessions, when she had to hold her arm high, and got a frozen shoulder. Pain could occur at any time during treatment. Another enlightening example of the differences between individuals was nausea. Having witnessed my mother endure chemotherapy, having read about possible side-effects of chemotherapy, and knowing my own distaste for nausea, I anticipated that all participants who had chemotherapy would be distressed by nausea. I was surprised to find that was not the case. Of the 6 participants who had chemotherapy, some were distressed by nausea, others mentioned it but were not distressed by it, and some did not discuss nausea at all. It became clear to me that even when participants shared the same treatment stage, the effects of that treatment were not identical. Participants experienced different effects, and even different levels of the same effect (e.g., low grade nausea to extreme nausea). Whether or not they found any particular thing distressing depended on their subjective experience of the event or process.

The diversity of responses from the participants made it seem, at first glance, that there was little these women had in common. However, closer inspection revealed that the different responses could be organized under seven common themes that reflected the women's core experiences. A conceptual ordering of the seven themes is presented in Figure 1.

*Overview of Themes*

It is apparent from the interviews that for these women breast cancer treatment had many dimensions. It was temporal, with discrete stages that were time-limited. It was dynamic, and presented demands that continually changed over time and forces that sometimes conflicted (e.g., wanting information in order to be prepared but not receiving guidance from a physician). From the women's perspective, there was a dynamic inter-relation amongst the themes, with themes having the ability to affect one another. In Figure 1 the sun indicates the women's perceived interactions amongst the themes. Further, the women felt that their responses and other contributing factors (e.g., receiving support from others) influenced future conditions and responses.

I anticipated that the women's responses would generate some themes that were stressors, and others that were coping strategies. In addition, I thought there might be some clear relationships between which coping strategies were helpful for certain stressors. However, I found that the themes reflect the complexity of these women's experiences during breast cancer treatment. Not all of the themes are clearly stressors or coping strategies, and there is not always a direct link between a particular stressor and a particular coping strategy.

One theme, "Physical Effects of Treatment" was comprised of stressors. Two themes, "Doing for Self" and "Thoughts to Self," were composed of activities that helped the women cope with their treatment (coping strategies). The remaining four themes ("Dimensions of Time," "Being Prepared," "Emotionality During Treatment," and "Support from Others") were either stressors, or coping strategies, depending on the circumstances and the particular woman.

From the women's perspective, the themes could influence one another. For example, "Dimensions of Time" was placed in a banner at the top of Figure 1 to indicate that time was both a theme and the context that treatment occurred in (e.g., treatment progressed through time,

the treatment stages were time-limited). Some women spoke of feeling distress when they felt treatment was progressing too quickly; a perceived fast speed of treatment was a stressor for these women. For one woman, the speed of treatment affected her ability to implement one of her preferred coping strategies. She wanted to prepare (theme "Being Prepared") for her treatment, but did not have the time to gather information. Her inability to prepare for treatment caused distress, and therefore, what could have been a coping strategy (being prepared through gathering information) became a stressor (unable to prepare). Another example of the perceived interaction between themes occurred for one woman between "Physical Effects of Treatment" and "Support from Others." She felt less distress when she was able to interact socially with friends. However, there were times during her treatment when she was too sick (a side effect of treatment) to be around people. The distressing physical effects of treatment meant she was not able to receive the support from friends that otherwise would have been available, and therefore the lack of support from her friends (theme "Support from Others") became a stressor.

In summary, the following seven themes are composed of themes that were stressors, themes that were coping strategies, and themes that were either stressors or coping strategies.

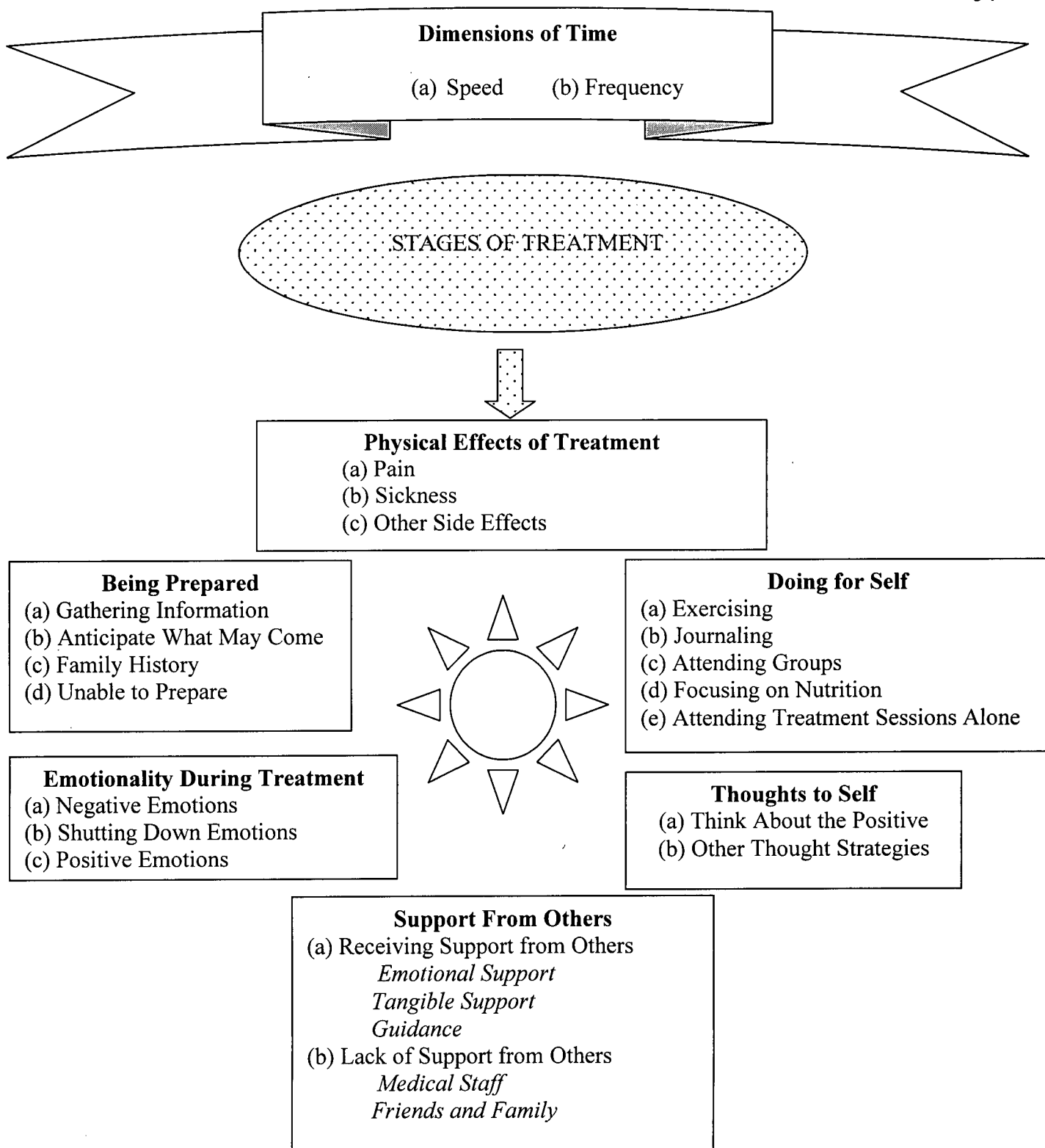


Figure 1. Conceptual framework of stressors and coping throughout breast cancer treatment.

## Dimensions of Time

Time was a dimension of treatment mentioned by all participants. Time could not be controlled by the participants, and was either helpful or distressing, depending on the woman. Two aspects of time were important to the participants, and are reflected in the sub-themes: (a) speed and (b) frequency.

### *Speed of Treatment*

The majority of the participants commented on the speed of their treatment, and found it to be either too fast or too slow. Perceiving treatment as very fast was not on its own associated with distress levels of participants; rather, feelings of distress seem dependent on the interaction between the perceived high speed, and the gestalt of what the participant was experiencing. Some participants who perceived various stages of their treatment as fast felt that the speed was helpful. Lynn (326) expressed her relief that her treatment occurred long enough ago that she did not have to endure a long wait for her surgery. "I was in for surgery the next week, so I only had a week to fret." Lisa and Judy reported identical feelings – both felt their surgery occurred quickly, and as Judy (808) stated, "I think that is a good thing." Sam was also pleased with how fast her treatment progressed.

In contrast, other participants were not happy with the quickness of their treatment. Throughout her treatment, Robyn (320) felt that each stage came upon her too quickly, and she found that distressing as she "thought she'd have a bit of time." Conny (170) also felt that the stages of treatment were fast, and stated: "I felt rushed into the whole thing." B. (17) found the speed of her lumpectomy stressful: "Once the surgery was done, that was it, it was just you were in, you were out. And that was pretty stressful."

Other participants perceived their treatment as slow, which in all cases was associated with distress. Mary (24) had a 5-week wait for her surgery, which she perceived as slow treatment:



“That was the hardest part, the waiting.” Conny commented on the slowness of the oncologists, and the long waits she experienced when attending appointments, which she found distressing. “They’re on their time,” Conny (400) stated: “They don’t give you the courtesy that, hey, you’ve got a life too.” One participant, Robyn (122), experienced a delay in treatment, when she was bumped for both lumpectomies: “Yeah, that part was kind of awful. Both times I got delayed.”

#### *Frequency of Treatments*

The frequency of the radiation treatments was distressing for some of the participants who underwent radiation. Radiation treatments were daily (excluding weekends), which meant that participants had to travel each day to attend radiation sessions. Judy, Sam, and Conny identified the daily travel as stressful. Judy (302) captured the feelings of the three participants when she said: “That was stressful. The going, you know, that it’s so regular.”

#### *Summary of Dimensions of Time*

In summary, two dimensions of time (speed and frequency) were associated with the stress and coping experiences of all participants. Whereas perceived slow treatment was associated with distress for most women, perceived fast treatment could be distressing or helpful depending on the viewpoint of the particular woman. Frequency of treatment, specifically the daily travel inherent to radiation, was a stressful process mentioned by some of the participants who underwent radiation. For these women, time could be either a stressor, or a way to cope with the stress of treatment.

#### *Physical Effects of Treatment*

The physical effects of breast cancer treatment were difficult for the participants. Physical effects that were reported as being important to the participants fell into three sub-groups: (a) pain, (b) sickness, and (c) other side effects due to treatment.

### *Pain Associated with Treatment*

Pain was a physical effect of treatment that was present at different stages for different participants. Some participants had difficulty with pain after their surgery. Lynn experienced noteworthy pain after both her first lumpectomy and her double mastectomy. After the freezing wore off from her first lumpectomy, Lynn (21) remembered thinking: "Ouch, this hurts so much, can I even drive home?" After her double mastectomy, Lynn (395) did not experience distressing pain until a nurse unwound the bandages during a home-visit:

When she unwound the bandage I went into severe pain. I guess it put me into shock... I don't know why that caused such severe pain, but it just felt like at that exact moment, someone had cut them both off.

Lisa (449) also experienced pain after her lumpectomy: "And I looked at her [sister], and I was in a lot of pain, because the anesthetic had worn off, and I didn't take any painkillers, and I was uncomfortable, my arm was really, really hurting me." The radiation treatments were difficult for Sam (261), who developed a painful frozen shoulder during each session:

The radiation was probably the worst because I got a frozen shoulder and it was so painful because you have to lie on a table for 15 or 20 minutes with the arm way up and you can't move. And I had tears pouring down my face because it hurt so much. And having to do that every day. That, I think, is stressful entirely.

Some participants experienced pain when on tamoxifen, a hormone treatment that induces a chemical menopause. Lisa (187) had pain in her joints, and would occasionally need to take a sick day due to pain:

The most difficult effect was those on my joints. Some mornings I would be very, very stiff. I felt like an old lady, you know, like I had arthritis? And I don't, I don't have arthritis. That was the difficult part, the stiffness of this treatment.

While on tamoxifen, Judy (665) experienced pain when she walked, and decided to terminate this treatment early: "It was just a physical thing, I mean you're taking something that results in you're hurting to move. You know, it makes you re-think that pretty quickly."

### *Sickness Associated with Treatment*

The women in the study experienced sickness at various stages of treatment. Some became sick from the anesthetic they received during surgery. Lynn (155) woke up from her second lumpectomy “sick as a dog.” “I could wake up just enough to vomit and then fall back asleep.” Robyn (113) also felt ill after her first lumpectomy, despite having told the doctors she needed something for nausea: “Even though they told me the first time that they’d give me something to help, it didn’t.” Chemotherapy was difficult for several participants who felt sick during treatment. “You definitely do feel lousy, there’s no doubt about that,” asserted B. (206). Diane would sometimes stay in bed due to feeling weak with nausea. Cleo (481) had a terrible time during chemotherapy:

Constant nausea really got to me, because you feel like death. I remember saying to R. I’m not doing this again. I mean, if they ever recommend chemo again, forget it, you know, I’ll just call it game over at that point rather than do that.

### *Other Side Effects due to Treatment*

Other than pain and sickness, participants experienced a variety of difficult side effects that depended on the type of treatment they were having and how that treatment interacted with their body. The women reported distressing levels of fatigue at various stages of treatment. Robyn (463) endured fatigue during her radiation treatments:

That was tough, especially when I started the radiation and they talk about fatigue, and I never experienced fatigue like that before. I’d be sitting here on the couch watching T.V., thinking I was resting and my body would be like, no, you have to lay down right now, I felt like I had no choice, I just had to lay down flat, it was like I’d never had that kind of fatigue before. It was amazing.

Diane (19) found fatigue debilitating during chemotherapy: “I was going once a month for treatment, and the most debilitating effect was on your energy levels. I was just so tired all the time, and I found my brain wasn’t working all that well...” Radiation was also difficult for Diane

(183): “Again, I found it really affected my energy level. Physically it is demanding on the body, and I was really tired again.”

In addition to fatigue, participants discussed a host of side effects that included hot flashes, night sweats, weight gain, hair loss, and sores. Tamoxifen causes a chemical menopause, and some participants found those symptoms very disturbing. Robyn (645) felt tamoxifen was the “worst thing,” and stated: “That’s a part of the whole thing I hated the worst because it gave you menopausal symptoms.” Sam (180) found the various side effects of chemotherapy “gruesome.” Cleo (454) struggled through chemotherapy, and said, “I would say the physical misery through chemo was the thing that really got to me.”

During treatment, participants found themselves in a difficult position – they knew that the treatment was intended to heal, but they were experiencing distressing side effects. B. (385) summarized the feelings of many:

You know both the chemo and the radiation, your intellect tells you, you know why it is being done, the reading, you’re informed, but the actual experience of it is: the chemotherapy, they’re putting chemicals in your body that aren’t just destroying the cancer, it’s making your hair fall out, it’s making your eyelashes fall out, it’s giving you sores on your tongue, it’s doing this, you can’t eat, the radiation, you know what goes through your mind, I was quite fortunate, I didn’t get the burn, but that’s all going through your mind, your skin’s going to be burned, it can affect the bones, is it radiating something it’s not supposed to radiate?

### *Summary of Physical Effects of Treatment*

In summary, the physical effects of breast cancer treatment were distressing for many participants. Any particular physical effect could range in severity (e.g., low-grade nausea to severe nausea and vomiting), however, the physical effects reported by these women were the ones that appeared to be associated with the most distress. For these women, many physical effects of breast cancer treatment perceived as stressors.

## Being Prepared

Participants spoke of being prepared for the different stages of treatment they were about to face. 'Being prepared' meant different things to different participants, reflected in following four sub-themes: (a) 'Gathering information,' (b) 'Anticipate what may come,' (c) 'Family history,' and (d) 'Unable to prepare.' Some anticipated things that might happen during treatment and took steps to be prepared for the possibilities, whereas others had a feeling of being prepared for treatment because of their family history of breast cancer. In these instances, being prepared, either through action or through past experience was helpful to the participants. However, wanting to be prepared, but being unable to take action to prepare, was noted by some participants as being stressful.

### *Gathering Information*

Many participants talked about the reading they did during treatment for breast cancer. Sometimes this reading helped them make a decision about where to go next in treatment, as in the case of Lynn (33): "From what I've read, I decided to have both breasts removed because the literature said lobular would almost always occur in both [breasts]." More often, reading was something proactive the participants could do as they went into various stages of their treatment. This proactive stance was reflected by B.'s (293) comment, "I armed myself with information, that's what I did." Participants often did large volumes of reading. Cleo (101) stated, "They give you this book, it's a 300 page book on being a partner in your care. So I read the whole thing." Sam (117) said, "I read everything I could get my hands on and I went on the Internet." However, the desired information was not always easy to access, as pointed out by B. (765):

There's so many times when instead of, you know, you just can't pick up the phone and talk to your doctor, you have to look, you've got to get on the web site, you've got to look for this, you've got to look for that.

Lisa (232) also noted the difficulty of accessing certain information, and wondered if this was to increase compliance with treatment: "And you know, they don't give you all this information, you have to search it for yourself. And I suppose if they did, you wouldn't do the treatment that you have to." Sometimes this quest for knowledge became consuming, as explained by Robyn (343): "I was reading about cancer, I had a hard time not treating that just as my job. Spending all that time, and just doing research. I did a lot, especially on tamoxifen." In addition to reading, participants gathered information by talking to a person who had specialized knowledge. Sometimes this was a physician. Sam and Mary both chose to interview multiple physicians as they gathered information during treatment. Some sought information from other medical professionals, as demonstrated by Lisa (236), who frequently spoke with the pharmacist at the hospital:

I mean, they give you enough information, they say, these are the side-effects, and some affect some people more than others, but some of them they don't mention. So what I did, I was in touch with the pharmacist at X Hospital, where I got my medication, and I would phone and say: "Look, T. tell me about this."

Several women chose to speak to women who had previously been through breast cancer treatment, the helpfulness of which was captured by Cleo (177):

That was enormously helpful to have that sense of someone who has been through it, knows what is involved, can tell you the upside, the downside, wasn't necessarily giving me advice, but just telling me the possibilities of what might happen. And just knowing someone who had gone through it, had probably the worse prognosis and scenario than I did, and was still doing fine, is just encouraging.

### *Anticipate What May Come*

For some participants, part of being prepared was anticipating what might happen during different stages of treatment, and then doing something that made them feel ready to proceed with treatment. Some participants took some form of action, as in the case of Judy. Judy prepared a freezer-full of food before radiation treatment so that if she experienced a great deal

of fatigue she had the option of not cooking. Lynn also took action, choosing to go back to work in the week before her double mastectomy. Lynn (330) stated, "I felt I needed to go back and spend one week explaining to each of the children why I'd be away for the rest of the year." Other participants chose to set aside time to think about what may happen, and then made a decision that increased their feeling of preparedness. Based on a book she had read, Robyn made a decision before attending her first radiation appointment that she would use the technique of visualizing the radiation light as a healing light in order to reduce her fear. For Cleo, being prepared for treatment meant discussing all eventualities with her husband. Specifically, Cleo wanted to decide if suicide would be an option if she had a poor prognosis and a lot of pain. Cleo (135) said:

So we started talking about what we would do, and he was clear that if it came to that, he would help me in any way that he could, if we had to do that. So once I confronted that, I thought if I can feel OK about dying, the possibility of it, then I can just get on with the rest of it.

### *Family History*

For some participants, being prepared for treatment did not entail specific actions taken, such as gathering information and anticipating what may happen, but rather replying on their previous experiences with breast cancer in their families. Both Conny and Lisa witnessed their mother's breast cancer treatment, and both participants felt this helped to prepare them for their own breast cancer treatment. When reflecting on her experience, Lisa (115) wondered how she managed treatment, and stated: "Possibly the preparation, I think. The preparation I had." Conny did not feel adversely affected by her breast cancer treatment, and attributed her feelings to her mother's attitude during and after treatment:

And just her [mother] whole attitude, and her whole acceptance of it, and she never bothered doing any reconstruction or anything, and I would see her in all her glory and there was not a problem. So it didn't bother me either.

### *Unable to Prepare*

Participants spoke of how being prepared helped them with their treatment. However, when participants were unable to prepare, the lack of preparation became distressing. Inability to prepare was sometimes due to time pressures, as experienced by Diane (4), who began treatment within 2 weeks of diagnosis: "It was a little overwhelming because I didn't have a chance to gather a lot of information." Other participants found they were too ill to prepare in the manner they wanted, a situation summarized by B. (779):

What happens with cancer is each step of the treatment you're not thinking about it until you're there, and sometimes you're there, you're so tired, and you're so sick, and you're that. You just don't have what it takes to be arming yourself with the knowledge.

### *Summary of Preparing for Treatment*

Participants expressed a desire to be prepared for the stage of treatment they were facing and felt prepared when they were able to gather information or take a specific action that they found helpful. Some participants felt prepared by their previous experience with their mother's breast cancer treatment. Being prepared, through an action or family history, helped the women to manage the distress they were experiencing and was one way to cope with the stress of breast cancer treatment. The inability to prepare (e.g., due to illness or time constraints) was associated with distress and was therefore a stressor experienced during breast cancer treatment.

### *Emotionality During Treatment*

All participants spoke about their emotions during breast cancer treatment. Among the 10 participants a plethora of emotions were reported, the lion's share of which were negative. In retrospect, some participants recognized that they shut down their troubling emotions. Few participants reported any positive feelings. This theme is composed of three sub-themes: (a) negative emotions, (b) shutting down emotions, and (c) positive emotions.



### *Negative Emotions*

Negative emotions were emotions that participants found distressing or troubling. Participants experienced negative emotions both in anticipation of a particular stage of their treatment, and throughout the treatment stage. In the time leading up to different stages of treatment, participants reported experiencing anticipatory negative emotions, such as anxiety, fear, and worry. These emotions seemed to stem from the unknown – participants did not know what their experience was going to be like. Judy (39) reported being fearful before her lumpectomy because of her “fear of not-knowing”. B. (527) found the first day of chemotherapy stressful because “you just don’t know what you’re going into.” Anticipatory negative emotions had the potential to contribute to participant’s feelings of isolation, because, as expressed by Diane (135): “I was so frightened about it [mastectomy], that I found it difficult to talk to people about it.” Knowledge was not necessarily helpful in alleviating these negative emotions. Before her lumpectomy, Mary (68) experienced fear, and attributed her fear to the knowledge she held from her former career as a nurse. “Because I was a nurse myself, so I was aware of all the possibilities, of all the things that could happen.” Robyn (343) also found that the knowledge she gained from reading was causing her distress: “It’s all the reading, and thinking, oh, I’m going to have permanent damage to my lungs.” In fact, Judy (49) was cautioned by her physician to not read too much:

I can see the value in that because I read everything I could get my hands on and, of course, I would think that I was the worst-case scenario. You know, this would happen to me, and that would happen to me. So I probably had myself more anxious than I would have had to be.

Throughout the treatment stages, participants experienced a wide variety of negative emotions that seemed to be reactionary. There were multiple factors that appeared to contribute to the negative emotions experienced by the participants, and it is probable that not all factors were made explicit in each interview. Two of the contributing factors that were reported by all

participants were: (a) the nature of the treatment, and (b) the effects of the treatment. The nature of the treatment referred to the characteristics of the treatment. This included the physicality of treatment (e.g., the specialized rooms in which the participants received treatment), the structure of treatment (e.g., when appointments had to be booked), and the specialized medical staff with whom the participants had to interact (specifically physicians). The effects of treatment included the effectiveness of treatment (i.e., was it working?) and the side effects of treatment. Side effects could be physical (e.g., nausea and pain), or they could be emotional (e.g., depression due to medication-related hormonal changes).

The nature of treatment was difficult for participants. Specifically, treatment in particular medical settings were difficult. Going into the operating room was difficult for Diane (127): "It's like going into a torture chamber. I mean, emotionally, that's how it seemed." B. (412) found that "chemo and radiation was a pretty freaky thing." The radiation room isolated the women, as explained by B. (372):

The most stressful thing about radiation is the actual – I mean, having x-rays is one thing, when you go into a room where the doors are that thick, and you actually see the symbol on the door, and those people go behind the little – you know when you have x-rays they go behind the little door in the same room, you go for radiation and there's nobody in the room with you. It's a very isolating experience.

The first appointment for radiation entails measuring and mapping (marking with permanent tattoos), and subsequent appointments are daily. Robyn (336) summarized this distressing experience: "The whole process was intimidating. Just having to go and get mapped out, and get your little tattoos, and having permanent tattoos, and then thinking what it is doing to your body." The permanent tattoos were particularly distressing for Judy (247):

You know they do that first appointment for measuring, and just emotionally that really hit me, that really upset me. I guess these permanent marks that I have. I mean, there are two permanent marks that really upset me.

Robyn (353) also found the permanent tattoos distressing:

I mean, someone else looking probably won't notice, but I notice. You've got this permanent alteration to your body, this permanent reminder, and you're wondering, well, I guess they have to do it, but is there some way they can do it that is less invasive?

The daily appointments were also difficult. Some participants found it impossible to structure their days to their comfort level. "It felt very disempowering to have no control over my life that way," remembered Judy (544). "That was frustrating for me because I can't say if I can do this next week because I don't know what time my radiation is."

Interacting with medical staff also contributed to negative emotions. In particular, participants pointed out the difficulty of their relationships with their physicians. Judy (65) felt "unsupported" and "unempowered" by her surgeon. B. (779) desired knowledge, and was frustrated when her physician was unable to provide sufficient information:

You know, I'm sure it's like that with a lot of things, but you're going through the treatment, you just magically figure that whoever you're seeing knows all the answers and they just don't. So it can be a bit frustrating.

Robyn (796) was annoyed with the lack of knowledge displayed by her oncologist:

I got some lymphedema, which I found difficult, too...but I called the oncologist and he said you can't get lymphedema if you haven't had chemo. [Robyn met with a physiotherapist] I'm in there, she measured my arms and said "yes", ordered me the sleeve and she said, "I don't know what the heck he's talking about," and she showed me from *Abreast in the West* an article a month or two before talking about radiation lymphedema. I thought, "What an idiot." That was really annoying. He didn't know what he was talking about.

The effects of treatment were something that each participant struggled with, particularly the effectiveness of treatment in terms of whether or not the treatment was working. Cleo (504) felt anxious throughout her chemotherapy: "The anxiety, was it doing any good, or you know, has it spread, was I going to find out at some point that there is somewhere else?" Although she completed chemotherapy and radiation, Sam (342) wondered at the point of it all:

I didn't feel quite comfortable that the radiation was in fact necessary... that all seems so primitive to me, you know, that chemotherapy is toxic to your body. Radiation is another sort of killer, and I was feeling this is so primitive, I mean they might as well be using knives, and I wonder if the radiation was necessary.

B. had a pacemaker, so was faced with the additional question: Was the chemotherapy and radiation going to affect the pacemaker? B. (496) reflected:

My pacemaker works on demand, I knew the pacemaker did it's job, and I wasn't too concerned if the pacemaker didn't work for a few days because I knew what my body normally would've done under that circumstance. But it was a little stressful wondering what the chemo had actually done, and what the radiation was doing, and that everything would work properly.

Side effects were a major issue for participants. Sometimes the physical side effects meant that the participant could not do something she wanted to do. Lynn (483) had time off from work after her double mastectomy, but the physical effects of surgery kept her from pursuing her gardening. "I relished the 6 months off work, but I was incredibly impatient with the fact that I didn't heal up and have a lot of energy to do all the things I wanted to do in that time off." Judy (608) was unable to do some household tasks due to her lumpectomy:

I had to send the laundry out after my surgery, that was hard to do, because I don't work. You know, this is my job, being a homemaker, and I couldn't do it, couldn't move my right arm, couldn't do it. So that was a bit difficult. Not financially, it was fine, but emotionally it was a little bit tough to need help to do that.

Robyn (820) developed lymphedema from radiation therapy and was frustrated when she lost the full use of her right hand: "That was really frustrating, because being right-handed... everything on the right." The physical side-effect of some treatments prevented Diane (65) from getting the social interaction she needed:

In the end it was isolation, a lot of it was the result of not having the energy to participate, not having the energy to interact with people. And I forced myself to go to these support groups, and to these relaxation sessions at the clinic regularly, because I found that really helped to boost my spirits. But sometimes I just felt like staying in bed because I was weak, just a low-grade nausea that accompanied the treatment. And so that was the worst part.

Cleo (487) was also ill from treatment, and wondered how she would get through it:

I was feeling quite despairing through chemo, I mean I just really wondered if I could tolerate it. How much of it could I put up with? It was like having a really bad flu, everyday. Wondering if I would ever feel the same again.

Some participants experienced depression. Sam saw a psychiatrist during treatment because of depression. Moreover, Diane (75) thinks the physical side effects contributed to her depression:

Because I was so tired I found it difficult to think. I had trouble keeping up with the news, or even a long conversation. So that, I think, was the most difficult part. I think I got depressed as a result.

Lisa (147) experienced depression, an emotional side effect of medication, while she was on tamoxifen: "It also caused a bit of depression, in the beginning. It's a physiological reaction."

In summary, participants reported a variety of negative emotions during treatment. These negative emotions occurred at all stages of treatment, in anticipation of something, or in reaction to what the women were experiencing. Whatever the origin, these women found that negative emotions were a distressing aspect of treatment.

### *Shutting Down Emotions*

Two participants identified that they shut down their troubling emotions. In retrospect, this seemed to be how they identified their emotional states, and not a decision they made at the time of treatment. Diane (192) felt disturbed by her feelings of isolation during radiation therapy, and stated: "I just kind of bottled it up for awhile." Robyn (58) found the speed of her treatment stressful, and felt she handled the stress by "going into survival mode." Robyn (66) explained this state further:

You're shut down emotionally. You're just doing what you have to do and not really being all that emotionally present. So, it's like, OK, I have to do this, and not being able to think about the future. So that real sense of each day by itself is all I can think about, don't ask me about tomorrow. Just have to think about today, and get through today. And then the next step, whatever that is.

### *Feeling Positive*

Only two participants mentioned that they had positive feelings during treatment. Lynn (90) recalled her positive feelings at the time of her first lumpectomy, and stated: "I felt quite positive

and not very concerned at all.” Lynn attributed this positive feeling to her nature of assuming the best until she knows the worst, and did not feel it was a coping strategy. Lynn went on to have an additional lumpectomy, a double mastectomy, and almost 5 years of tamoxifen, throughout which she reported many negative emotions. Lisa (72) reported feeling positive throughout her breast cancer treatment: “So that’s how it felt, that was my reaction. It was not negative, I was not depressed, I was very affirmative.” Lisa (299) attributed her positive feelings to her belief in empowerment: “I think you have to empower yourself, empowerment is the key.” She felt that her positive feelings provided her with the ability to handle treatment.

#### *Summary of Emotionality During Treatment*

In summary, the majority of the emotions reported by participants was negative, and could be classified as anticipatory or reactionary. Each participant’s experience of treatment was unique, as well as their view of the world and resources. Thus, there was a range of reported negative emotions. These negative emotions were a distressing aspect of treatment for these women, and contributed to the stress the women felt during treatment. In comparison to the large frequency and range of reported negative emotions, positive emotions occurred rarely. In retrospect, two participants felt they shut down their emotions, and this “shutting down” seemed to be an automatic response that helped the women to deal with the stress of treatment.

#### *Support from Others*

Participants spoke about the support from others they received, and noted that the support from others helped them to deal with distress during breast cancer treatment. ‘Support’ was present in three different forms: (a) emotional support, (b) tangible support, and (c) guidance. Participants felt emotionally supported when others expressed their care and concern, listened to participants’ worries, and spent time talking with, or just being with, participants. Some

participants received tangible support (e.g., help with cooking, laundry, driving) that was helpful. Other participants appreciated the guidance (information and knowledge) offered by others.

The women in the study experienced distress when they desired or expected support from others, and support was not received. Therefore, this theme 'Support from Others' is composed of two sub-themes: (a) Receiving Support from Others (which was helpful), and (b) Lack of Support from Others (which was distressing). Within the sub-theme 'Lack of Support from Others' participants desired all three previously mentioned forms of support (emotional, tangible, and guidance). The distress associated with a perceived lack of support stemmed from the women's desire for support from two main groups of people: (a) the medical staff, and (b) friends and family.

#### *Receiving Support from Others*

*Emotional support.* Participants received emotional support from a number of sources. B. (45) did not want to be alone after her lumpectomy, and spent a lot of time with family and friends. "I didn't want to be here dealing with it on my own, in the beginning." Lynn (408) also surrounded herself with friends and family after her double mastectomy: "My coping in that period was probably a lot of reaching out to friends and family." Some people expressed their concern by sending cards and gifts, and participants found this supportive. Lisa (89) said, "And I had tremendous support, even at work, my co-workers... I had so many flowers at home that I didn't have any more room. It's true, I mean, it's just amazing, the support." Sam (533) received gifts from her discussion group: "I mean, they all gave me food and they all gave me wishes and concerns. Friends really did want to do stuff... That was nice." Judy (591) also felt supported when she received gifts:

There was another thing that was tremendous. I got over 20 bouquets and gifts and things from people, which was really neat, that was a neat gift of the cancer experience to know that I was cared about by these people.

Participants also felt emotionally supported when people spent time listening to, and talking with them. Judy (319) stated that “just a lot of talking” was helpful to her. Diane (102) was able to talk to a couple of “phone friends” that she made from a support group. Robyn (563) felt helped when she attended a retreat and met people who would let her speak: “It was effective because I was not only finding people had similar circumstances, but also finding people who understood what I was talking about and allowed me to talk about that.” Cleo (240) felt very supported by her husband, who listened to her concerns, and talked with her about them, despite his own preference to not talk:

He was very, very supportive through this whole thing, and he just said to me, very explicitly: “Whatever you need, in any way, if you just need to talk about things, whatever, I’m very willing to do that.” And he did... And when I’d wake up at 2 in the morning and be in that state of anxiety, he would be very comforting, and again very willing to talk. So, it was clear to me that he put his own needs aside, totally, and was just willing to do this whole thing with me, which I really appreciated.

Sam (188) had a poignant experience during a chemotherapy appointment, when she became acutely distressed, and received emotional support from a social worker. The social worker sat with Sam, and listened to her, and encouraged her to talk about her distress:

That was a real turning point. I’m sure there are other good words for that. It was very significant. And I kind of loved that social worker. I feel she wouldn’t remember me now from Adam, but I felt totally bonded with her because I shared that.

Emotional support did not have to come from a human being, as Robyn and Lynn found.

After her double mastectomy, Lynn (465) would “sit around and pet my different kitty cats, and walk the dogs.” Robyn (483) felt supported by her cat: “I had a cat at the time, and that was it. And she was a great source of comfort, so we spent a lot of time together, cuddling.”



*Tangible support.* Tangible support was concrete help that was offered to participants, such as doing the driving, doing the laundry, and cooking meals. B. (35) received help from family members after her lumpectomy: "My mother-in-law showed up the next day and proceeded to cook, which was wonderful. My mother came and wanted to clean. I allowed that to happen, just took that in." Robyn (85) had a friend who helped her with household tasks after her first lumpectomy:

He was always really helpful. If I needed laundry done, he'd take my laundry away and do it for me and bring it back, and cook me dinner, and do all sorts of great things for me. So that was helpful.

Some participants received rides to their daily radiation appointments. Sam (304) said: "So, sometimes friends drove me and that was nice." Judy (266) was "glad" to receive rides from friends to radiation therapy. Conny also felt supported by her friends who volunteered to drive her.

*Guidance.* Judy (163) spoke about the guidance she received from a friend who had previously been through breast cancer treatment: "She was a good resource for me." In addition, Judy (168) found the information she got from a member of her spirituality group helpful: "A woman in my spirituality group is a nurse and I was able to phone her with questions." Mary (51) also received information from her daughter, who is also a nurse, "that was useful."

In summary, participants felt less distressed when they received support from others. The three types of support that were important to participants were: emotional, tangible, and guidance. Tangible support and guidance were concrete things that other people offered to the participant. Emotional support seemed to be more a matter of how the participant interpreted the interaction, as illustrated by the participants who felt supported by their pets.

### *Lack of Support from Others*

*The medical staff.* Participants did not always receive the support they wanted from the medical staff (e.g., physicians, nurses, technologists) with whom they interacted during their breast cancer treatment. Participants looked to medical staff for all three types of support: (a) medical staff could offer guidance because they held information that the participants wanted, (b) medical staff could offer tangible support in taking care of the physical needs of participants that arose during treatment, and (c) participants wanted to feel like they were being heard, so medical staff could provide emotional support by listening, and responding in a meaningful way.

Lynn did not get her physical needs met after her second lumpectomy. "I woke up sick as a dog," Lynn (155) remembered:

They were trying to get me out of the hospital, but I couldn't fully wake up. I could wake up just enough to vomit and fall back asleep. And I can remember hearing this vague fog, the nurse saying to my husband, "Look, you've got to get her out of here, we're closing, this is the day surgery." And he says, "Well, what do I do? She can't walk." And they pulled over a wheelchair, and I remember them just kind of flopping me into it. And pushing me to the door and then flopping me into the car. I really can't remember coming home or anything.

This lack of tangible support from the nursing staff placed Lynn (164) in a distressing situation. "It was scary being half-awake and weak, and I couldn't fully wake up. And them saying, 'You got to go, you've got to get up and go.'"

Frequently, participants were distressed by the lack of guidance provided by the medical staff, notably their physicians. Judy (30) took a list of questions to her surgeon on the day of her surgery, and did not feel she received adequate information. "He just grabbed the list and said, 'Yes, no, nah...' and zonk, I was out. I didn't feel too comfortable having answers to my questions." Robyn (894) felt that neither her oncologist nor her family physician was well informed about breast cancer treatment: "just not feeling that you have an oncologist or GP or anyone that really knows a lot of information." Robyn (780) was particularly distressed by the

lack of knowledge displayed by her oncologist: "I talked to him, and I wasn't very impressed with him anyway, he was quite young and I didn't find him very knowledgeable. That was another stressor." In fact, while doing some research of her own, Robyn (818) discovered her oncologist had given her incorrect medical information: "I thought, 'What an idiot.' That was really annoying. He didn't know what he was talking about." Sam (22) was "surprised in a negative way" at the attitude of her physicians when she wanted to go across town to get a mastectomy with simultaneous breast reconstruction. This combined surgery was not done in her area of the city, and she expected her physicians (who had guided her through two lumpectomies) to share her medical information with her new surgeons across town. However, what Sam (23) experienced was a "lack of communication" between the doctors in the two areas of the city. "I could tell there was a protection feeling about the doctors in the [area of city]. Like, why do I think I have to go over town to get better treatment? That was surprising" (Sam, 32). To get the treatment she wanted, Sam (25) felt like she "had to take charge," which added to her distress levels.

Participants also desired emotional support from medical staff. Sam (486) felt "the whole radiation process was very cold." In particular, Sam (493) mentioned her radiation oncologist, who was "just business-like." "I don't know what I wanted," Sam (494) mused, "but I didn't get it." The end of each treatment stage was an opportunity for medical staff to provide some emotional support, perhaps by reassuring participants and listening to their thoughts and concerns, but it did not often happen for these women. After her lumpectomy, B. (22) felt that she did not receive support:

I just thought there was going to be a little more to it, you know, staying in the hospital, a little bit more than just being booted out the next day and sent home. To deal with it, basically you feel like you're being sent home to deal with it on your own.

The end of radiation was distressing for some participants. Judy (469) found the lack of emotional support at the end of radiation jarring: "In [area of city] it's a very supported, loving situation. You go every day, and everyone's friendly and you're getting all this attention and support and all of a sudden it's over. It's like, what do I do now?" Judy (811) added that there was no support system set up for her to access:

I mean, as soon as they write you off, you're not able to phone the Cancer Center, anything. Once your name is off their list you have no access, you're done, you're done. Somebody else's turn. You can see that, there's a lot of people, 18,000 every year in BC, diagnosed with cancer. So, you can see that, but it feels like you're left adrift.

B. (597) also felt unsupported at the end of radiation, and was fearful:

Because that's really what the feeling was, now what do I do, oh my God? You know, 9 months of chemo, and then 16 days in a row of radiation. So there was always someone looking at you, poking at you, asking you how you were, taking your temperature, taking your blood pressure, taking your heart rate, checking this, checking that, and now we're done with you, see you in 6 months. That's pretty scary.

Sam felt a connection with one member of the radiology medical staff, and on her final treatment day she wanted to say good-bye. That staff-person was not working on Sam's final day, and Sam (513) remembered how she felt:

I was sorry about that because I couldn't...there wasn't anyone meaningful that I could say good-bye to. And it's just over time, you... I don't know... they say even women who have been raped sometimes want to talk to their abuser. Just because there's some bond, it may be negative, anyways, it was kind of like that. There's all this involvement and then, nothing.

B. (616) felt that the distress some patients feel at the end of each treatment stage could be alleviated if the specialists made an effort to talk to the patient and provide some reassurance:

[radiation is the] Same as chemo, you see the doctor before, but you don't see anyone after. I think if there was just that little reassurance, that this is normal, that is the normal way things work, we feel really confident that the 16 treatments have helped...if you have any questions or concerns before we want to see you in 6 months, give us a call. I think approachability, if you felt that they were a little more approachable.

Participants desired all three types of support from the medical staff with whom they interacted. When this support was not forthcoming, participants felt distressed. The end of each

treatment stage seemed especially important to participants; at this time in particular they craved some form of meaningful interaction with medical staff (e.g., reassurance from their physician, some form of good-bye with staff).

*Friends and Family.* Above all, participants hoped their friends and family would provide emotional support. Participants wanted family and friends to spend time with them – listening, talking, and just being with them. Several participants experienced distress when they felt they did not receive support from their family and friends.

Sometimes, participants were too physically unwell to access the emotional support that friends could provide. Although Cleo (416) found emotional support from her friends helpful after her surgery, she was too sick during chemotherapy to be around them. “I was feeling so unwell, I just couldn’t do pretty well anything socially, like I had social things I wanted to go to and I couldn’t go to them.” Cleo’s friends offered to come to her home, but Cleo (579) said: “I really didn’t want to be around people that much. I felt too unwell to be able to enjoy the people being there.” Diane (65) was also too sick during chemotherapy to interact with people, and found the isolation distressing: “In the end it was isolation, and the isolation, a lot of it was the result of not having the energy to participate, not having the energy to interact with people.”

Other times, participants felt that friends and family did not want to, or were unable to offer emotional support. Robyn (623) said: “I don’t feel I had a lot of support from my family.” Robyn (621) felt she couldn’t talk to anyone: “Your friends and family don’t want to hear it. It’s just too scary for them.” When Diane (169) had her mastectomy, one of her “closest support people” was her mother. Although Diane would have liked to talk to her mother about the surgery, Diane (171) felt she could not share her feelings: “She [mother] found it very difficult to cope with the prospect that I was going to lose a breast. She just didn’t want to talk about it.” As Diane’s (199) treatment progressed, she felt that her family was unable to offer as much emotional support as

she needed: “By this time I felt my family was burned out, so my closest support systems, which were my parents and sister, they just seemed to be – I felt like they were getting depressed.” Judy (183) felt abandoned during her treatment: “I had two close friends who abandoned me and that was hard... And I know that one of them was depressed. That’s true, but that doesn’t seem like a very good excuse to me.”

### *Summary of Support from Others*

There were three types of support that were important to the participants: emotional support, tangible support, and guidance. Participants indicated that support from others was helpful, and allowed them to better deal with the stressors they were experiencing during their breast cancer treatment. Accessing support from others was a coping strategy for these women. However, when participants desired support from others, but did not receive it, the lack of support was associated with distress (lack of support was a stressor for these women).

### *Thoughts to Self*

Participants spoke about getting through distressing times during treatment using specific thoughts. These thoughts were represented as private and did not appear to be shared with others. The theme ‘Thoughts to Self’ encompasses two sub-groups that were important to participants: (a) think about the positive, and (b) other thought strategies.

### *Think about the Positive*

Several participants used positive thoughts to help them deal with distressing times during treatment. Some participants experienced distress at the beginning of treatment. Conny (454) thought about the strength she had that would carry her through treatment. “You know, maybe in the beginning I thought, oooh, and then, oh well, I’m a survivor, I’m gonna just carry on.” Robyn (442) was distressed by the speed of her first lumpectomy, and was helped by her thought: “Well, it’s probably good to get it over with.” Lynn (113) reported little distress surrounding her

first lumpectomy, and attributed this lack of distress to her thought that it was caught early:

“Because at that point I thought, it’s early and mild, and nothing much to worry about.” Sam (68) stated that she was less distressed in general than she could have been because of how she thought about breast cancer:

I had never expected to get cancer. It was never in my family. It was not in my mind as a possibility. So I think in a way I might be more distressed, but I just saw it as something that shouldn’t have happened. It was going to be a challenge. And I would get over it.

As the participants progressed past the first stage of their treatment, they continued to think about the positive aspects. After her second lumpectomy, Lynn was faced with the possibility of a mastectomy, and the need to take time off work. Lynn (178) stated that for the past several years her job had “been quite stressful,” and when she thought about a potential mastectomy she also thought about the upside: “I remember thinking, well, it won’t be so bad if I have to have a mastectomy, I can take a 6 months leave of absence. There’s a bright side to it” (Lynn, 113). B. (426) wanted to think positively during her radiation treatment sessions, and used music to help her focus her thoughts.

They would say, “Is there a particular kind of music?” I say, “Yes, can you put some Bob Marley on?” Boom – like that, no questions asked...I could feel a little more positive, and think more positively about what was going on, and why it was going on.

Judy (867) felt distress that her radiation treatments were damaging healthy tissue, too, and reminded herself why she was doing radiation: “Because while you’re going through radiation, you’re thinking, well, this is a pain, but I’m doing this to help myself. This is for my own good, even though it is killing healthy cells.” In the early stages of her chemotherapy, B. (273) realized she needed more time to deal with the side effects that chemotherapy was causing. She had to temporarily stop work, and felt distress: “In the beginning, definitely I felt like this isn’t fair, we’re not going to be able to get a trip to Mexico this year...” B. (261) was helped when she thought about how things would be later: “Once you get into it, and you realize that by stopping

working for 6 months you're going to be so much better down the road, it becomes easier, a whole lot easier."

Positive thoughts helped participants deal with the distress they experienced during treatment. In some cases, the participants actively found positive thoughts that were helpful to them (e.g., the benefits of radiation, how things would be better later). In other cases, the positive thoughts seemed like an automatic response that stemmed from participant's view of the world (e.g., Lynn initially thought the best; Sam thought breast cancer should not have happened to her).

### *Other Thought Strategies*

In addition to 'thinking about the positive,' participants used an assortment of other thought strategies. These strategies were intended to help alleviate the distress participants were feeling. The women chose specific thoughts that were helpful to them, based on their personalities and ways of thinking about the world.

Sam (119) used statistics to help her throughout her treatment. When she felt distress, she would think about the calculations she had done:

What I mainly did, and again it helped me emotionally, and it's probably how I deal with a lot of things – I really love statistics. So, I worked out all of the statistics because my case didn't fit any one thing, so I would take the probability of this and work it all out to an 85% chance of survival over 5 years... which initially was kind of scary, but anyway I guess I find comfort in numbers, and I thought, an 85% chance of living. That's pretty good. So that's the way I probably dealt with it.

Chemotherapy was difficult for Cleo (454) due to a number of side effects that resulted in "physical misery." To help get through chemotherapy, Cleo (540) did a day-by-day counting down of time, and also thought ahead: "I tried to project ahead, saying, well, by Christmas this will be all over, by New Year I'll be able to do other things, maybe I'll go back home, see my family."



Several participants used specific thought strategies during radiation therapy. Judy (533) stated she had a “need to plan things,” and found the daily travel required during radiation therapy distressing, because she was not able to plan other activities. She decreased her distress when she made a decision about how to think about her life: “I just decided that my life was going to get this narrow for this period of time” (Judy, 549). Conny (229) identified the daily travel as the most distressing aspect of radiation therapy, and dealt with it by thinking about radiation as a job: “I just put it into my routine. I don’t work, so it was like a job.” Judy and Robyn both chose to visualize the radiation light as a healing light to decrease their distress. Robyn (448) described the strategy: “So that was a technique I used, I thought, I’m going to use that technique to bring the light in and see it as a healing light. And try to reframe that so I’m not so afraid of it.”

#### *Summary of Thoughts to Self*

These women found certain ways of thinking helpful when they experienced distress during treatment. One common strategy was to think about the positive. Some participants actively chose to think about the positive, while others had positive thoughts that stemmed from their world-view. The women also found other thought strategies helpful in reducing distress, e.g., calculated survival statistics, projected ahead. For these women, their thoughts to themselves were ways of coping with the stress of treatment.

#### *Doing for Self*

Throughout treatment, participants chose to do some activities purely for themselves, with the intention of helping themselves deal with breast cancer treatment. Which activities participants found helpful depended on each participant’s way of being in the world (e.g., finding participation in a group helpful vs. an activity done alone). The activities that were mentioned by

the participants were: (a) exercising, (b) journaling, (c) attending groups, (d) focusing on nutrition, and (e) attending treatment sessions alone.

### *Exercising*

Some participants found that exercise helped them during their breast cancer treatment. Judy (93) stated that since her lumpectomy, exercise became “very important” in “handling stress in general.” Mary (157) noted that many people have “awful stories” about chemotherapy, but noted: “I think if you can keep going, that’s really important.” Mary (148) kept up her habit of exercising, even during chemotherapy. “I kept up with exercise, with walking. Every day, regardless, and I think that was really important.” Lisa (193) spent years on tamoxifen, and power-walked: “Now, during those years I did a lot of power-walking...daily. A lot of moving and walking, and that helped.”

### *Journaling*

Judy has journaled for many years, and found it helpful during her treatment. “Journaling is huge. It’s a huge coping mechanism for me,” Judy (84) stated. “It helps me to clarify my feelings and my thoughts and it also helps me to let go of them, like once I put it on paper then I don’t have to carry it around.”

### *Attending Groups*

Two participants found attending groups helpful. Robyn (422) attended relaxation groups at a variety of places during her radiation treatment, and found them helpful: “[relaxation groups] Just helped me because I felt tense all the time, I felt like I couldn’t relax. That was my biggest thing, it’s like I can’t relax. It’s like, this is my job, its cancer.” Diane (87) also found relaxation groups helpful throughout her treatment:

I was so tired it was difficult for me to register how distressed I was about the whole experience, and the impact it might have on my life. I mean, I felt better after I went. So I knew there was something positive about that.

In addition to relaxation groups, Diane (68) found support groups useful: "I found they really helped to boost my spirits... knowing other people that were going through it helped, and talking to people."

### *Focusing on Nutrition*

Some participants found that focusing on their nutrition was helpful during treatment. Mary (190) found paying attention to nutrition especially important during chemotherapy, when she had to modify what she ate because of side-effects: "Nutrition is important, and fluids and stuff. You lose the taste for some things, and other things appeal to you. So you have to modify." During radiation, Judy visited with a dietician at the Cancer Clinic. She used the information from the appointment to modify her eating habits, and made a lot of healthy dishes from scratch. "That's good, it feels good," Judy (515) asserted. Lynn (517) focused on her nutrition during her 4.5 years on tamoxifen, and felt that was a way to cope with the treatment: "I also became much more interested in diet and vitamins and things... So that, too, was probably a coping kind of thing." Lisa also focused on nutrition during tamoxifen treatment, and said friends who specialize in nutrition helped her develop a nutritional approach to follow during those years.

### *Attending Treatment Sessions Alone*

Two participants chose to attend their treatment sessions alone. Although she had offers of rides, Mary (168) chose to drive herself, alone, to her radiation appointments:

But I drove myself always to that, except for one day, and I found that good, because if you drive with people, people like to talk. I'm not a good communicator, I like to be by myself. So that worked well.

B. (332) chose to attend all her chemotherapy and radiation treatments by herself: "It was something I could control, it was something I could do for myself."

### *Summary of Doing for Self*

There were a variety of activities that participants chose to do in order to help them deal with the stressors they experienced during treatment. Whether the activity was done within a group (e.g., attending a relaxation group), or done by the individual (e.g., journaling), the commonality of these activities was that the focus was on the “self”. What the women chose to do, and what they found helpful as a coping strategy, depended on each woman’s unique way of being in the world.

### Summary of Findings

Semi-structured interviews were used to gain insight into breast cancer treatment for 10 women, and to answer the question “At each stage of breast cancer treatment, what was the most salient stressor and how did the women cope with that stressor?” The seven themes that emerged indicate that for these women, breast cancer treatment was a complex and dynamic process. The themes cannot be clearly divided into “stressors” and “coping strategies,” and reflect the dynamic quality of stress and coping during breast cancer treatment for these women. Whether something was a stressor or a coping strategy for the women often depended on the perceived interactions amongst the different components of breast cancer treatment. It was difficult to find many clear relationships between stressors and coping strategies (i.e., ‘x’ was a stressor, so the women did ‘y’). Treatment presented a variety of stressors, and different women could experience identical stressors (e.g., pain) at different stages of their treatment (e.g., feeling distressing pain after surgery versus feeling distressing pain during radiation therapy sessions). Sometimes the women chose a particular coping strategy in response to a stressor. Other times the women enacted a coping strategy to deal with the distress they were feeling, but did not link the strategy with any particular stressor. Still other times, from the women’s perspective, the stressors influenced the desired coping strategies of the women so that they themselves became stressors. To understand

stress and coping during breast cancer treatment, the entirety of the experience, and the unique needs and characteristics of the woman undergoing treatment must be considered.

## CHAPTER FIVE

### DISCUSSION

Breast cancer is a major health concern for Canadian women: 1 in 9 Canadian women may expect to develop breast cancer in their lifetime (Canadian Cancer Society website, 2006). Women who are diagnosed with breast cancer go on to have breast cancer treatment, and must find ways to cope with the stressors that treatment presents. Despite the impact that breast cancer treatment has on Canadian women, there is little research that has investigated stress and coping during the entirety of the treatment process. Moreover, few studies have focused on treatment as a process, linked the coping strategies with the stressors, and attended to the women's context. Thus, the question that guided the present study was: "At each stage of breast cancer treatment, what was the most salient stressor, and how did the women cope with that stressor?"

Before discussing the findings, it is important to acknowledge that the women's characteristics may have influenced the nature of the findings. All of the participants in this study were Caucasian, all were middle to middle-upper class, and most had a university education. In addition, the participants were volunteers, indicating that they placed enough importance on the research to share both their time, and their personal experience with breast cancer treatment.

#### *Placing the Findings in the Context of the Current Literature*

Because of the effect that breast cancer can have on a woman's breasts, the social discourse surrounding breast cancer speaks about the disease as a threat to femininity and sexuality (Landmark & Wahl, 2002; Thorne & Murray, 2000). In contrast to the dominant social discourse, Langellier and Sullivan (1998) found that the women in their study ascribed different meanings to their breasts, based on what was important to them. Femininity and sexuality were not necessarily threatened for these women during their experience with breast cancer. The present study offers support for that finding, as distress due to the effects of breast cancer

treatment on their breasts did not emerge as a dominant theme. In fact, in the present study, there was very little talk amongst participants regarding their breasts. When they did talk about their breasts, most participants pointed out that survival was more important than concerns about their breasts. These comments regarding the greater importance of survival mirrored quotations provided in a study by Landmark and Wahl (2002).

Time was an interesting phenomenon in the present study. It could act as a stressor or as a coping strategy, depending on the viewpoint of the particular woman. These effects of time have been uncovered in other studies. As in the present study, Landmark, Strandmark, and Wahl (2002) interviewed 10 women, and analyzed the data for common themes using the procedures from Grounded Theory. These authors found that long waiting times during treatment caused distress for the participants in their study. With respect to the speed of treatment, and identical to some of the women in the present study, Saares and Suominen (2005) found that some women felt that they “benefited enormously” from the “immediate start-up” of their treatment. One woman in their study stated that the quick start to her treatment “felt good,” a feeling that was echoed by Judy in the present study. How time affected the women in the present study depended on the interaction between their appraisals of time and their unique view of the world.

All of the women in the present study found the physical effects of treatment distressing. Identical to other studies, the women in the present study reported a variety of distressing physical symptoms, such as pain, nausea, vomiting, and fatigue (Cowley et al., 2000; Fischer, 2001; Saares & Suominen, 2005; Thomas-MacLean, 2004; Wengstrom et al., 2001). Sometimes, these physical symptoms were so overwhelming that the women felt they were simply surviving, and not effectively coping. Perhaps the women’s inability to mobilize effective coping was due to the fact that their illness sapped their health and energy, two coping resources (i.e., resources people draw on to facilitate coping) mentioned by Lazarus and Folkman (1984).

In addition to the physical effects of treatment, the women in the present study experienced distressing emotions throughout their treatment. Some women experienced anticipatory negative emotions before particular stages of treatment, in part due to the fact that they did not know what was going to happen. The present study replicated findings from other studies that some women experience anticipatory fear, anxiety, and worry, before certain treatment stages begin (Jacobsen, Bovberg, & Redd, 1993; Montgomery et al., 2003; Saares & Suominen, 2005; Thomas-MacLean, 2004).

Negative emotions continued to be distressing throughout treatment for the women in the present study, and were attributed to two things: (a) the nature of treatment (i.e., the physicality and structure of the treatment) and (b) the effects of the treatment (i.e., the side effects and the effectiveness of treatment). The negative emotions that the women in the present study found distressing during treatment included anxiety, frustration, and annoyance. Women in a study by Lethborg, Kissane, Burns, and Snyder (2000) also spoke about the overwhelming psychological nature of treatment. These authors interviewed 8 women with early stage breast cancer who had completed chemotherapy between two to four weeks previously, and asked them about their experiences with treatment. Some participants stated that the emotional effects of treatment could sometimes be harder to deal with than the physical effects. Some women in the present study found that there was a point at which they shut down their distressing emotions, a similar finding to Lethborg et al., who found that the women in their study had times where they concentrated on survival, and had a blinkered approach to their treatment. The findings from the present study and the study by Lethborg et al. indicated that both physical and emotional effects of treatment could be overwhelming for some women. It is therefore interesting to note that very few studies ask women the about the details of their emotional distress during treatment; in contrast, many studies lump all distressing emotions under the titles of “distress” or “stress”



(Koopman, Hermanson, Diamond, Angell, & Spiegel, 1998; Gallagher, Parle, & Cairns, 2002; Manne, Winkel, Ostroff, Grana, & Fox, 2005). The variety of negative emotions reported in the present study indicated that “emotional distress” could have many different components, depending on the particular woman and her unique situation and circumstances.

Dunn and Steginga (2000) suggested that women at different life stages find different events stressful when experiencing breast cancer. Specifically, these authors stated that “young” women have unique concerns. The participants in the present study ranged in age from 47 to 74 years old; some were pre-menopausal when they experienced breast cancer treatment and some were post-menopausal. Despite the variety in life-stages, the women in the present study were a cohesive group with respect to what they considered stressors during breast cancer treatment. The findings of the present study suggest that age may not dictate what women find stressful during breast cancer treatment.

The women in the present study rarely reported positive emotions, and only one woman stated that her positive emotions helped her cope with treatment. Use of positive emotions as a way to cope with breast cancer treatment has been found in other studies (Fischer, 2001; Wengstrom et al., 2001). Although not a prevalent coping strategy in the present study, it seems that some women find positive emotions a useful coping strategy. It is not possible from the present study to determine if women who use positive emotions as a coping strategy have shared characteristics.

The variety of coping strategies reported by the women in the present study mainly involved some form of action taken. The women indicated a desire to be prepared for treatment, and several women felt prepared when they gathered information about their upcoming treatment. Having information allowed the women to make decisions about their treatment, and be ready for the possible effects of treatment. Other studies have also found that some women desire

information (Landmark et al., 2002; Saares & Suominen, 2005), and a study by Rager (2003) uncovered identical motivations for gathering information. The sources the women in the present study used were also similar to those used by the participants in Rager's study: printed materials, the Internet, and experts (e.g., physicians, breast cancer survivors). The women in the present study also prepared in other ways, such as cooking sufficient food to last through radiation therapy. Some women felt prepared because of their family history of breast cancer. Being prepared, in whichever preferred manner, was important enough to the women in the present study that if they could not be prepared, they felt distressed.

The women in the present study used an array of cognitive strategies that included thinking about the positive and counting down the days. These cognitive strategies have been found in other studies that focused on the treatment aspect of breast cancer (Cowley et al., 2000; Lethborg et al., 2000). In addition to cognitive strategies, the women in the present study chose a number of activities (e.g., journaling, exercising) where the focus was on the self, and these activities helped them cope with treatment. Wengstrom et al. (2001) also found their participants used self-oriented activities to cope with treatment.

Seeking support was the final active coping strategy that was used by the women in the present study. The women identified three types of support that was helpful to them: emotional, tangible, and guidance (i.e., informational). Receiving the support they desired helped them to cope with treatment, whereas not receiving the support they wanted was a stressor. These findings are consistent with the literature, which has found both evidence that emotional, tangible, and informational support is helpful to women undergoing breast cancer treatment, and that a lack of those types of support are associated with distress (Hirschman & Bourjolly, 2005; Landmark et al., 2002; Landmark & Wahl, 2002; Lethborg et al., 2000; Lugton, 1997; Saares & Suominen, 2005; Wengstrom et al., 2001).

Some researchers note that emotional support from family was the most important type of support, in contrast to the present study where one type of support was not markedly valued over the others (Landmark et al., 2002; Landmark & Wahl, 2002; Lethborg et al., 2000). A notable aspect of the present study was the lack of support that several women experienced when they interacted with the medical staff. The lack of support from the medical community has been found in other studies, where women did not feel that they received adequate emotional support or proper guidance from their physicians (Landmark et al., 2002; Landmark & Wahl, 2002). Some women in the present study felt the lack of emotional support from medical staff particularly keenly at the end of their treatment. Judy commented that she felt "left adrift," an almost identical comment to one by a participant in Lethborg et al.'s (2000) study, who said she felt "cast adrift." Thomas-MacLean (2004) also found that the end of treatment was associated with distress for some women. It is clear from the findings of the present study, and the current literature that support from others is an important coping strategy for women undergoing breast cancer treatment.

### *Stress and Coping During Breast Cancer Treatment*

The findings from the present study are discussed in terms of Lazarus and Folkman's (1984) transactional model of stress and coping. First, I focus on the appraisals made by the women during their breast cancer treatment, given that appraisals are a central construct in the transactional theory. Then, I consider the major stressors the women identified, along with common coping strategies. Finally, I consider the relevance of the transactional model in understanding the experience of women who are coping with breast cancer treatment.

From the themes that emerged in the present study, the women appraised a number of concerns as taxing or exceeding their resources and endangering their well-being (i.e., primary/secondary appraisal) throughout their breast cancer treatment. The appraisal process of

each individual was unique, as illustrated by the concept of time. The appraisals the women made specific to the dimensions of time depended on their unique relationship with the environment. What each woman appraised as stressful depended on her particular values, beliefs, and resources. Some women perceived that their treatment was progressing “too fast,” and found the speed of treatment stressful. Other women perceived their treatment as “too slow,” and this perception was associated with distress. Still other women perceived their treatment as “fast,” but did not find the speed stressful. These women appraised the speed as a good thing – they coped by viewing the speed of their treatment as positive.

The themes that emerged in the present study represent the events that these women found to be stressors, and what they used as coping strategies throughout their breast cancer treatment. All of the women appraised the physical effects of treatment as distressing, and some women lacked confidence in their ability to deal (i.e., cope) with the stressful physical effects of treatment. Some women found there were times during their treatment when they were so sick that they did not even think of coping; during these times they existed at a primal level of survival. Many women found that the physical effects of treatment interfered with their ability to implement coping strategies. In fact, some women decided that they could not actively cope with the harm the physical effects were doing to their bodies, and terminated treatment early (i.e., coped by avoiding treatment). The women’s struggles to cope with the physical side effects of treatment indicated the overwhelming nature of breast cancer treatment, and offer an example of a time when finding effective means of coping may not be possible. In addition to the physical effects of treatment, the women also experienced other events as stressors: (a) the negative emotions (e.g., anxiety, fear) that accompanied treatment, (b) not being able to prepare for treatment in their preferred manner (e.g., problem-focused coping), and (c) not receiving the type of support they desired from others.

Illustrated by the themes, it was apparent that the women in this study used a number of problem-focused coping strategies to deal with the stressors they experienced during treatment. Some women gathered information, and others took action in order to be prepared for the difficulties of treatment. Sometimes the women received tangible support (e.g., help with chores) and guidance (e.g., information from a breast cancer survivor). Some of the activities the women chose to do to help them feel better during treatment were also problem-focused coping (e.g., focusing on nutrition in order to help strengthen their immune system). The women also used a variety of emotion-focused coping strategies, given that they were unable to change the course of their treatment; they were able to change how they thought about it. Moreover, some of the support the women received from others could be considered emotion-focused coping (e.g., distracting themselves from the stress of treatment through socializing with family and friends). The women also used strategies such as focusing on the positive aspects of treatment instead of dwelling on the distressing nature of their treatment.

Lazarus and Folkman's (1984) theoretical framework contributes to an understanding of the women's experiences in treatment. By elucidating the appraisal process it provides a method of determining which events were stressors, and what were coping strategies. The theory states that there can be dynamic interplay amongst appraisals, which this study supports. The theory also suggests that an examination of the appraisal process should uncover a link between stressors and the coping strategies intended to modify the situation. Those links were not clear in the present study. The women were able to identify the most salient stressors of treatment, and they were able to identify the strategies they used to cope with the stress of treatment, but they did not often link their coping strategies with any particular stressor. In addition, Lazarus and Folkman's theory was chosen as the framework both because of its dominance in the psychosocial literature on stress and because it addresses the process-nature of breast cancer treatment. As I attempted

to illustrate in Figure 1, the present study did not find a clear progression of coping strategies over time, rather, it was evident that for these women there were dynamic interactions amongst their perceived stressors and the coping strategies they mobilized during their breast cancer treatments.

One reason for the lack of a progression of coping strategies may be the fact that, for these women, each treatment stage did not have its own set of unique stressors. Treatment progressed through time, and one treatment stage gave way to the next, but the stressors did not clearly change from “Stressor Set A” to “Stressor Set B” and so on. Therefore, the coping strategies also did not have clear changes over time. The lack of a strong link between stressors and coping strategies may be an artifact of the recall design. Perhaps if the women were interviewed at each stage of treatment there would have been a stronger link between particular stressors and the resultant coping strategies. It is also possible that a longitudinal approach would have captured the changes in coping strategies over the span of treatment.

To me, breast cancer treatment for these women seemed to be like a “tumbleweed.” The prickly branches of the tumbleweed consisted of all the stressors that treatment presented, and all the coping strategies the women implemented. The stressors and the coping strategies (the branches) were intertwined, overlapping and influencing each other. The treatment tumbleweed moved forward in time, from the start of treatment to the end.

### *Limitations*

Ten Caucasian women participated in this qualitative study, all were middle to middle-upper class, and most possessed a university education. The qualitative nature of the study, the small sample size, and the participants’ characteristics mean that the findings are not generalizable to other samples. However, the findings can be used to generate an understanding of potential

stressors and coping strategies that may be mobilized during breast cancer treatment, and that understanding can aid in clinical work with other populations.

The participants and my interactions with them defined the information that resulted from the interviews. It is possible that the women who were interested in participating in such a study were different in some fundamental way from women who were not interested. This may have affected the type of information that was gained from the study. For example, perhaps the women who participated in this study were women who experienced comparatively less distress than other women. Or perhaps the participants were women who felt they coped well, or in a manner they found positive, with the distress of treatment. I do not know if these hypotheses are true, but it is interesting to note that the women in the present study predominantly used active coping strategies, perhaps suggesting that these women possessed the combination of coping resources, view of the world, and the environment that allowed them to do so.

The research interview was my first face-to-face meeting with each participant. We did not have an established relationship based on mutual respect and trust, so it is possible that there were stressors or coping strategies that were important to the women, but which they were not comfortable sharing with me. I took a number of steps to ensure the interviews were safe for the participants: (a) obtained ethical approval from the University of British Columbia Behavioural Research Ethics Board, (b) signed a detailed consent form that outlined the participants' rights and the steps taken to ensure confidentiality, (c) answered all questions before the interview started, and (d) provided an outline of the questions so the participants knew the direction of the interview. However, some aspects of breast cancer treatment are personal, and despite these steps the possibility remains that some women were not comfortable sharing all of the salient details of their breast cancer treatment.

The present study relied on participants' memories of their experiences during breast cancer treatment. In addition, the interviews were conducted at least one year post-treatment. It is possible that the women did not recall all the stressors and the coping strategies they used. I addressed this concern by asking the women to recall their most salient stressor, and the ways they coped with that stressor. My assumption was that the women who were interested in this research and chose to participate placed meaning on their experience, and remembered the details that were the most relevant to them.

### *Implications for Practice*

The present study stands apart from the majority of the breast cancer literature because it illustrates in detail the individuality and complexity of the appraisal process. The findings also clearly demonstrate that different women find different aspects of treatment stressful, and indicate that clinicians may want to consider taking the time to explore the treatment experience in detail with each client, rather than assuming the stressors presented by treatment are identical for all women.

The present study revealed that there were times during treatment when the physical side effects were overwhelming, and the women felt like they could not implement effective coping strategies. The inability to effectively cope during these times may have been due to the fact that they did not possess two necessary coping resources: energy and health. This raises the important consideration of what types of coping resources women possess. For example, in the present study, the women were all of a socio-economic class that afforded them certain luxuries, such as a home computer. Several of the women coped with the stress of upcoming treatment by using the Internet to find information. Women who do not have access to a computer are unable to cope in this manner. If this is how the women prefer to cope, the findings of the present study indicate that this inability to get information may become an additional stressor. When working



with a client who is undergoing breast cancer treatment, counsellors need to be aware of their client's preferred coping strategies, and whether she has the coping resources that will allow her to implement those strategies. In addition, it is beneficial to be aware that times exist when women undergoing treatment are overwhelmed, and that supportive counselling would probably be more useful to the women during those times rather than attempting to provide in-depth counselling.

Several of the coping strategies used by the women in this study were centered on the self, however, support from others was a coping strategy that required input from people surrounding the women. Therefore, it is important to remember that women undergoing treatment exist in the context of their relationships with others. An especially noteworthy finding was the distress associated with a lack of support from the medical community, specifically at the end of treatment. This finding indicated that if we follow the medical model, and direct psychosocial services only at diagnosis and treatment, then we are missing a time of need for the woman with breast cancer.

### *Suggestions for Future Research*

The present study uncovered the salient stressors and coping strategies for the 10 participants, however, it did not find a link between particular stressors and coping strategies, nor did it find that certain coping strategies were more useful during one treatment stage than another. Perhaps a different study design would capture changes over time. Wengstrom et al. (2001) found changes in coping strategies over time within one particular treatment stage with the use of a longitudinal design, and although the authors did not focus on the stressors, they presented some aspects of the psychological situation of the women, such as sadness and worry. Future studies that examine stress and coping throughout treatment and use a longitudinal design may capture changes over time, and find links between stressors and the coping strategies.

The present study found a number of emotional stressors, a finding that coincides with a study by Lethborg et al., (2000). Instead of grouping all emotional stressors under the title of “distress,” future studies could investigate the emotional side of breast cancer treatment.

Support from others was a key coping strategy for the women in the present study. There are a number of avenues of research that stem from this finding. Receiving support was helpful to the women, but may have had an associated cost for the support-giver. For example, one participant in the present study noted that her desire to know and discuss every detail of her treatment was in direct opposition to her husband’s preference to avoid distressing information. Future research could investigate the impact that breast cancer treatment and women’s preferred coping strategies have on different relationships, for example, spousal relationships and mother-child relationships. A perceived lack of support was distressing for the women in the present study, especially the lack of support from the medical community at the end of their treatment. Most participants noted that they felt supported and cared for throughout treatment, which made lack of support at the end of treatment particularly jarring. This merits further investigation, if future studies can uncover what women need at the end of treatment to feel supported, perhaps some form of psychosocial intervention can be put in place.

The participants in the present study were 10 Caucasian women, middle to middle-upper class, and most possessed a university education. The characteristics of the participants may have influenced the findings. Of note was that the participants used predominantly active coping strategies, in contrast to other studies that have also found passive and denial coping strategies (Edgar, Remmer, Rosberger, & Fournier, 2000; Heim et al., 1997). Replicating this study with participants with different backgrounds (e.g., different socio-economic class, different levels of education, variety of ethnicities) may give some insight into how the participant’s characteristics influence the coping strategies.

## Conclusion

The present study explored the most salient stressors and coping strategies throughout breast cancer treatment for 10 women. Lazarus and Folkman's (1984) transactional theory of stress and coping provided the theoretical framework for the concepts of "stress" and "coping." This ensured that the meaning of "stress" was phenomenologically based, and that "coping" was construed as a process. The interview process incorporated these two concepts, the definition of "stress" was made explicit to the women, and the women were asked about their coping strategies at each stage of treatment.

The transcripts of the interviews were analyzed free from the bonds of theory, and seven themes emerged: (a) Dimensions of Time, (b) Physical Effects of Treatment, (c) Being Prepared, (d) Emotionality During Treatment, (e) Support from Others, (f) Thoughts to Self, and (g) Doing for Self. The appraisal processes of the women were unique, and depended on each woman's interaction with her environment, a finding consistent with Lazarus and Folkman's (1984) theory. In addition, the appraisal processes were complex and dynamic, which is also suggested by the theory. However, two suggestions of the theory, links between stressors and their coping strategies, and changes in coping strategies over time, were not apparent in the themes. Two possibilities may have contributed to these discrepancies with the theory: (a) an artifact of the recall design, and (b) for these women, each treatment stage did not have a unique set of stressors.

For women in the present study, breast cancer treatment presented a number of stressors, and was sometimes overwhelming. When overwhelmed, the women focused on survival, and when they possessed the necessary coping resources they mobilized predominantly active coping strategies. For these women the journey through breast cancer treatment was not a solitary one,

but one undertaken with their personal resources and abilities, and within the context of their relationships with family, friends, and the medical staff.

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## Appendix A

## Summary: Demographic Information and Treatment

B. is 50-years old, and married with two children. She does not identify with any religion, and currently works inside the home. She completed Grade 12. B.'s breast cancer treatment consisted of a lumpectomy, a 12-week course of chemotherapy, and 16 rounds of radiation.

Cleo is 60-years old, and married with no children. She does not identify with any religion, and is a retired psychologist. Cleo hold a PhD. Cleo's treatment consisted of a lumpectomy, chemotherapy, and radiation.

Conny is 56-years old, and married with three biological children and three step-children. She is Baptist, and works in Sales. Conny completed Grade 12 and holds a Real Estate License. Conny's treatment consisted of a mastectomy, 6 months of chemotherapy, and 28 rounds of radiation.

Diane is 47-years old, and single with no children. She is Christian, and works as a Marketing Consultant. She holds an MBA. Diane's treatment consisted of a mastectomy, chemotherapy, and radiation.

Judy is 59-years old, and married with no children. She belongs to the United Church of Canada, and works in the home. She completed Grade 15. Judy's treatment consisted of a lumpectomy with lymph node removal, 16 radiation treatments, and 1 month of tamoxifen. Lisa is 55-years old, and married with two children. She does not identify with any religion, but considers herself very spiritual. She holds a BA, and works as a social worker. Lisa's treatment consisted of a lumpectomy and almost 5 years of tamoxifen.

Lynn is 59-years old and married with two children. She does not attend a specific church, but defines herself as "religious". Lynn holds an MA and works as a speech pathologist. Lynn's treatment consisted of two lumpectomies, a double mastectomy, and 4.5 years of tamoxifen.

Mary is 74-years old, and married with three children. She belongs to the United Church and is a retired RN. Mary's treatment consisted of a lumpectomy, chemotherapy, and radiation.

Robyn is 48-years old, and single with no children. She defines her spirituality as "Training in Power." She holds a BA and works as a case manager. Robyn's treatment consisted of two lumpectomies, 16 radiation treatments, and 2 years of tamoxifen.

Sam is 62-years old, and married with two children. She does not identify with any religion. She completed some university and works as an office manager. Sam's treatment consisted of two lumpectomies, a mastectomy, chemotherapy, and radiation.

## Appendix D

## Initial Telephone Contact

I am a graduate student at UBC in the Counselling Psychology program, and I am currently working on my thesis. The title of my research is: "Female Survivors of Breast Cancer: Perceived stressors and methods of coping during treatment". I am interested in what women find stressful during treatment for breast cancer and how they cope with, or manage, this stress. I feel this research will provide useful knowledge for clinicians in the field of breast cancer, and also for women who are experiencing breast cancer for the first time. If you meet the criteria for the study and agree to participate, the interview will be audio-taped and will take up to one hour. Would you be willing to answer the screening questions?

Screening questions:

1. Are you in the Vancouver area?
2. What was your treatment?
3. How long has it been since your last breast cancer treatment?
4. Did you take hormone therapy, e.g. tamoxifen or arimidex. If yes, when did you finish?
5. Have you had any recurrence of your breast cancer?
6. Are you currently being treated for any physical or mental illness?

If the inclusion criteria were not met:

I am not able to include you in this study because [I stated which criteria was not met, and why it was important to my research]. I very much appreciate your interest and willingness to answer my questions. Thank you for your time.

## Appendix F

## Outline of Interview Questions

1. To provide a context, tell me about your experience of treatment for breast cancer.
2. What did you find the most stressful/distressing about the surgery for breast cancer?
3. How did you deal with the most stressful aspect of the surgery?
  - a. What was your intent in choosing that method to cope with the most stressful aspect of surgery?
  - b. What things were effective in dealing with the most stressful aspect of surgery?
  - c. Knowing what you know now, would you do anything differently?
4. What did you find the most stressful/distressing about adjuvant therapy (chemotherapy, radiation therapy, hormone therapy)?
5. How did you deal with the most stressful aspect of adjuvant therapy?
  - a. What was your intent in choosing that method to cope with the most stressful aspect of adjuvant therapy?
  - b. What things were effective in dealing with the most stressful aspect of adjuvant therapy?
  - c. Knowing what you know now, would you do anything differently?
6. Is there any other stressful/distressing aspect of treatment you would like to discuss?

## Appendix G

## Demographic/Breast Cancer Information Questionnaire

The following information is meant to provide a description of the people who took part in this study. Please do not put your name on this sheet of paper.

Pseudonym: \_\_\_\_\_

Ethnicity: \_\_\_\_\_

Religion/Spirituality: \_\_\_\_\_

Occupation: \_\_\_\_\_

Highest educational level achieved: \_\_\_\_\_

Relationship status: \_\_\_\_\_

Number of children: \_\_\_\_\_

Age range (eg. 20-30, 30-40, etc): \_\_\_\_\_